iLizwe lam (My world): Xhosa-Speaking Parents' Experiences of Caring for a Child with Autism Spectrum Disorder

by

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DECLARATION

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ABSTRACT

Although there has been an increase in research on autism spectrum disorder (ASD) globally, especially in Western communities, there is little evidence of research exploring African communities; more specifically, the Xhosa-speaking community. Even though the Xhosa-speaking community constitutes 31% of the Western Cape population, little to no research has explored the lives of the Xhosa-speaking community in the Western Cape. To gather insight into what is known and understood about ASD and how the community reacts to the manifestation of ASD, parents of children with ASD were selected for the study. The Xhosa-speaking parents were situated in Cape Town, and their children attended a school that caters for learners with ASD. Parents are the first persons to be confronted with the challenges of the course of ASD. The aim of the study was to explore the experiences of Xhosa-speaking parents caring for their children with ASD. The study focused on understanding how the parents conceptualised ASD, their daily experiences, their experience of the reactions of the community, and the support they received. The researcher attempted to mediate a focus group. Owing to limitations, an individual semi-structured interview, and a joint interview with two other participants were conducted. To facilitate discussion, the participants engaged in a 'River of Life' drawing. It was found that there was limited knowledge about ASD in the community, which led to misunderstandings, limited support from the community, isolation, and a possible delay in support. The parents expected limited support from the community. Even so, the parents showed resilience and independence from traditional African beliefs and were able to adapt. The study provides an account of three mothers, and their experiences of the livelihood of ASD, in the Xhosa-speaking community. To gain more insight into how to guide, educate, and support the parents and community, further research on a larger scale needs to be performed.

Keywords: autism spectrum disorder, autism, caring, Western community, Xhosa community, Western Cape, experiences, challenges

OPSOMMING

Hoewel daar wêreldwyd ’n toename in navorsing oor outisme-spektrum versteuring (OSV) was, veral in Westerse gemeenskappe, is daar min getuienis van navorsing wat Afrika-gemeenskappe verken; meer spesifiek, die Xhosasprekende gemeenskap. Hoewel die Xhosasprekende gemeenskap 31% van die Wes-Kaapse bevolking uitmaak, het min tot geen navorsing die lewens van die Xhosasprekende gemeenskap in die Wes-Kaap verken. Om insig te verkry oor wat bekend is en verstaan word oor OSV en hoe die gemeenskap op die voorkoms van OSV reageer, is ouers van kinders met OSV vir die studie gekies. Die Xhosasperekende ouers was in Kaapstad gevestig, en hulle kinders het ’n skool bygewoon wat na leerders met OSV omsien. Die ouers is die eerste persone wat met die uitdagings van die verloop van OSV gekonfronteer word. Die studie het gefokus op begrip van hoe ouers OSV konseptualiseer, hulle daaglikse ervarings, hulle ervaring van die reaksies van die gemeenskap, en die ondersteuning wat hulle ontvang het. Die navorser het probeer om ’n fokusgroep te medieer. As gevolg van beperkings is ’n individuele semi-gestruktureerde individuele onderhoud en ’n gesamentlike onderhoud met twee ander deelnemers gevoer. Om bespreking te bevorder, het die deelnemers aan ’n Rivier van die Lewe-tekening deelgeneem. Dit is bevind dat daar beperkte kennis oor OSV in die gemeenskap was, wat tot misverstande, beperkte ondersteuning van die gemeenskap, isolasie, en ’n moontlike vertraging in ondersteuning gelei het. Die ouers het beperkte ondersteuning van die gemeenskap verwag. Nietemin het die ouers veerkragtigheid en onafhanklikheid van tradisionele Afrika-oortuigings getoon en was in staat om aan te pas. Die studie doen verslag oor drie ouers en hulle ervarings van die lewensbestaan van OSV in die Xhosasprekende gemeenskap. Om meer insig te verkry oor hoe om die ouers en die gemeenskap te lei, op te voed en te ondersteun, sal verdere navorsing van groter omvang gedoen moet word.

Sleutelwoorde: outisme-spektrum versteuring, outisme, versorging, Westerse gemeenskap, Xhosa-gemeenskap, Wes-Kaap, ervarings, uitdagings

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LIST OF ABBREVIATIONS

ASD:	Autism Spectrum Disorder
DALYS:	Disability adjusted life years
DSM-V:	Diagnostic Statistical Manual 5th Edition
ICD-10:	International Classification of Diseases 10th Edition
ICF-CY:	International Classification of Functioning-Child Youth
PPCT:	Process Person Context Time
SIAS:	Screening, Identification, Assessment and Support
SSA:	Sub-Saharan Africa
UNICEF:	United Nations Children's Emergency Fund
WHO:	World Health Organization

CHAPTER 1

CONTEXTUALISING THE STUDY

1.1 Introduction and Background

> *"Somalis in North America call autism the "Western disease" because there is no word for autism in the Somali language and because many believe it does not exist in Somalia" (Decoteau, 2017, p. 169).*

This statement seems to be increasingly befitting for African, non-Western South Africans, who seemingly have been confronted with the Western-initiated, autism spectrum disorder (ASD) in their communities. ASD can be defined as a neurodevelopmental disorder that hinders a person's ability to communicate and socially interact appropriately, and may also display "repetitive patterns of behaviour, interests and activities" (American Psychiatric Association, p. 50, 2013). Mthombeni and Nwoye (2018) note that the idea of ASD as a "mental health disorder" in the African culture has not yet been established. Although there is a global increase of research about ASD, limited studies have been completed that relate to the ways, beliefs, behaviour. and interpretations of the African culture, especially in the realm of psychology. The most recent statistics have shown the estimated prevalence of ASD to be 1-2% (Bölte et al., 2018), but the research largely originated in the USA and high-income countries, even though most people living with ASD come from low- to middle-income countries (Bölte et al., 2018; Guler et al., 2017).

South Africa is a diverse, multicultural, multilingual country with varied needs and beliefs, which makes it difficult to define how ASD is perceived and understood in this context. De Vries (2016) shows concern about the lack of research that has been completed in South Africa. Only 33 cases of research that studied ASD and Africa between 2002 and 2014 were found (Nasiorowska, 2015). This shows that the African population is underrepresented in research on ASD, especially in the South African context. More specifically, the roles of sociocultural factors, race, ethnicity, and the effect these can have on the possible diagnosis,

treatment, and management of ASD are not well-known (Viljoen et al., 2019). Bölte et al. (2018) argues that the symptoms of ASD are common across most cultures and countries. While this is true, the insight, the meaning-making of the experience, and the acceptance of the diagnosis, differ between the various contexts (Bölte et al., 2018).

The ways in which ASD is perceived and defined are still mainly rooted in Western cultural ideals and communities (Bakare & Munir, 2011; Chambers, et al., 2017; Mthombeni & Nwoye, 2018). This is problematic, as it tends to force its own autonomy upon the livelihood of the functioning of the African presence and existence. It is limited and biased in that it does not integrate a more indigenous, non-Western influence, which goes against the primary principle of inclusivity that society tends to encourage (Mthombeni & Nwoye, 2018). Berry et al. (2002b, p. 332) support this by stating that “psychology by nature is culture bound”, and that “each cultural population needs to develop its own psychology”

Nsamenang, an influential and important African developmental psychologist, provides some insight into the psychology of African communities by comparing the Western and non-Western African worlds (Hwang et al., 1999). Most of Western psychological research tends to be focused on the “individual as autonomous”, whereas in the African world, the individual “coexists with the community, with spirits and with the ecological environment” (Berry et al., 2002a, p. 106). Therefore, exploring African indigenous beliefs about illness and disorders in a culturally diverse country like South Africa needs to be prioritised. Firstly, increasing numbers of people are being diagnosed with ASD and are requiring more support (Mthombeni & Nwoye, 2018). Secondly, Mthombeni & Nwoye (2018) believe that this incoherence of understanding could prevent the population from receiving early and reliable intervention, as well as lead to a poor prognosis.

Parents are the social catalyst in starting the process of gaining more clarity and understanding of the manifestation and outcomes of ASD in their community. They are the first ones to experience the warning signs and process their children’s development. The parents’ openness in seeking help and feeling empowered to take the first step is dependent upon their

knowledge and awareness of ASD, as well as their motivation. (Viljoen, et al., 2019). Viljoen describes the central role parents play in this process. Additionally, Bronfenbrenner's (1979) bioecological approach, which is often used to understand child development, places the parents in the microsystem, the child's immediate environment (Predescu et al., 2018). Direct interaction takes place, to which the child is constantly exposed. This may be beneficial or harmful to their upbringing.

Thus, parents can be described as the "mediators between the child and the larger world" (Predescu et al., 2018, p. 33). They play a vital role in knowing the needs of their child(ren), family, and community. They are responsible for influencing the child's social setting, support system, relationships, as well as his or her exposure to stimulation and resources, which is especially important during the child's first few years of existence (Viljoen et al., 2019). Therefore, the possibility exists that they could be assisting in appropriating relevant ways of communicating with the community about ASD without causing stress or rejection. In addition, they could contribute to informing experts on the possible barriers and facilitators in the child's life that could lead to better support in the family (Guler et al., 2017). This possibly would reduce the unrealistic strategies presented to them by the Western world that are unrelatable and redundant.

According to research, none of the Western strategies have been found to be successful in the African context, as there have been no consideration of the process of adaption, the understanding of culture, and their differences and similarities, regarding the supportive strategies (Viljoen et al., 2019). Once there is better understanding of how parts of society function, it will enable the establishment of suitable assessment tools and strategies, adaptations, and programmes that can be implemented in similar contexts (Viljoen et al., 2019).

Over the past few years, there has been limited research on parents' experiences while raising children with ASD. According to Guler et al. (2017), only 13 peer-reviewed articles based on sub-Saharan Africa have been published, with 12 of them published over the last 10

years. In De Schipper and colleagues' systematic literature review, only 17 of 71 studies focused on the relationship between peers and/or parents who care for or interact with a child with ASD, and how it affects the child, family, and society (De Schipper et al., 2015). It is important to note that most of the studies were done in high-income countries. This poses a problem that mitigates the importance of parents' perceptions and knowledge of ASD and the valuable role they play in effective and early methods of intervention, especially in low-income countries. The Millennium Cohort Study found that families living with children with ASD are more vulnerable to mental health issues, poverty, and social exclusion (Dillenburger et al., 2015). Thus, importance is also attached to precipitating the protection and support of not only the child living with ASD, but also the functioning of the family as an entity.

Currently, limited studies are based on the experiences of black African individuals and/or parents and their understanding of ASD in the Xhosa community. According to Statistics South Africa (2019), of the "Mid-year population estimates" for 2019, the black African people make out about 81% of the South African population. Of the 81% of black-Africans, the Xhosa community constitutes 17% of the South African population (Lehohla, 2016). This shows that the Xhosa community forms an important part of our diverse South Africa. Gaining the Xhosa community's perspective could lead to better assistance for children with ASD and their families.

A gap in research exists on the Xhosa community's experience and perspectives of ASD in their own households. It is crucial that the people in the Xhosa community feel understood, that they feel their ideas and beliefs are accepted and valued. This could lead to willingness to be open to making adaptations in their microsystems, which could reverberate into surrounding ecosystems. Appropriate support can be provided for the children with ASD, by the assistance of understanding the needs, ideas, and beliefs of the Xhosa people and essentially the African culture. The initiation of early intervention could also curb the effect of stressful environments and feelings of rejection.

1.2 Motivation for the Study

A few years ago, and more recently, I worked as a tutor for children with ASD. As an educational psychologist in training, I was regularly confronted with children with ASD who were growing up in African communities. I had the opportunity to communicate with a few non-Western caregivers and parents about the diagnosis. It occurred to me that many of the parents had varying perspectives and ways of supporting their autistic children, compared to the Western views. I realised then that even I held assumptions that the Western aspects of understanding a disability was the only way to follow and abide by.

The confrontation of this concept, alongside the non-Western culture that seemed under duress to adapt, disturbed the inclusive perspective that I tended to follow. The inclusive perspective includes the outlook that all children should be accommodated and their differences accepted and encouraged. It gave rise to the following questions: Is it fair that the non-Western people must adopt the Western view? Is it possible to have both views integrated with the overarching perspectives of disability? Why do we tend to ignore or are ill-informed about the non-Western people's truth and understanding? What influences their differentiating perspectives of autism? What is their perspective, and how can this help to support a child with autism? I decided to explore this further and to ascertain better understanding of the possible influences that shape their perspective and the way they support their children.

As highlighted in the previous section, a gap is present in the literature in understanding the perspectives of non-Western communities. This is due to limited research with ASD children and their parents in the African and Xhosa context. The combined personal experience and literature gap motivated me to explore this aspect further. I hope that the study will contribute to exploration of the African perceptions of ASD research, which ultimately could lead to the development of interventions that are more accessible, culturally friendly, and appropriate for the Xhosa community.

1.3 Problem Statement

According to Viljoen et al. (2019), children who live in South Africa who do not turn seven in the calendar year, are provided with no early intervention support by the government, in terms of programmes, schooling, and other services. The South African Schools Act 84 (1996) states that school attendance is compulsory only from the age of seven. Thus, sending one's child to an early childhood development (ECD) centre, like a creche or pre-school, for stimulation or caregiving purposes is voluntary. This has implications for the early diagnosis of ASD in many of the African countries, as children tend to be diagnosed with ASD only when they start attending school (Wannenburg & Van Niekerk, 2018).

Although globally, the prevalence rate of ASD has been increasing rapidly. The lack of studies on the African continent points to unclear and absent prevalence rates in sub-Saharan Africa, as well as in South Africa (Chambers et al., 2017; Franz et al., 2017; Guler et al., 2017; Mthombeni & Nwoye, 2018; Nasiorowska, 2015; Viljoen et al., 2019; Wannenburg & Van Niekerk, 2018). Ultimately, there seems to be a lack of studies completed on the African continent and South Africa, which amongst other things is due to a delay in early diagnosis. The delay in ASD diagnosis creates a problem in African, Xhosa communities due to the evolving lack of knowledge about the characteristics and functioning of children living with ASD, as well as the emerging stigma associated with its manifestation. Contributing to the delay is the disproportionate amount of screening and assessment tools, as well as the lack of suitable intervention strategies adapted for Westernised environments (Chambers, et al., 2017).

Ravindran and Myers (2012) argue that even if the manifestation of a neurodevelopmental disorder like ASD has common features and can be identified across contexts as a stable signifier or red flag; it does not mean that the interpretation and acceptance of the characteristics will be the same in every culture or community. Although the latter statement shows relevance, Bölte et al. (2018) note that the Diagnostic Statistical Manual 5th Edition (DSM-5) and the International Classification of Diseases 11th Edition (ICD-11), tend to not

integrate the importance of the cultural context along with the power it holds over the functioning of people living with ASD.

Not viewing the child living with ASD holistically has implications, as it is known that in every community or environment, there are risk and protective factors that accumulate to either support the people in it or are detrimental to them (Ebersöhn & Eloff, 2006). However, this depends on the awareness, realisation, understanding, and empowerment of the community's characteristics (Ebersöhn, & Eloff, 2006; Franz, et al., 2017). Ebersöhn and Eloff (2006) advocate searching for the protective factors that are available in the community and making them known. It can provide the community with preventative strategies that could change the course of a poor prognosis of ASD, which suddenly becomes a reality for the child, the parents, and lastly, the community.

To engage in protective strategies, risk factors in the community need to be addressed. In a scoping review of sub-Saharan Africa by Franz et al. (2017), it was found that in the African cultures, there seemed to be various beliefs based on the origin of ASD and how to support a child with ASD. These beliefs, as well as the risk of limited exposure to the disorder and knowledge of ASD, as discussed previously, could contribute to the parents' reluctance in seeking professional medical help. It seems as if they rather seek support from traditional methods (Franz, et al., 2017). Franz et al. (2017) explain that the misunderstood behaviour and the insignificant, unmarked physical features of a child with ASD have proven to influence the role of the community in causing the family to feel rejected and subjugated to criticism and judgement. Therefore, a diagnosis of ASD could create confusion and conflict in the family system and the community.

In Chambers et al.'s (2017) study, which took place in an isiZulu-speaking community in Kwazulu-Natal; it was found that some parents experienced difficulty identifying the early signs of ASD. The researchers presented possible reasons for this: a somewhat limited knowledge of the manifestation of ASD, and varying perspectives on the social and developmental milestones that their children need to achieve (Chambers, et al., 2017). Along with these

issues, the community cohesively stigmatised the behaviours and symptoms of a child with ASD(Chambers, et al., 2017).

Little is known about the influence of a child living with ASD in the Xhosa-speaking community. The parents of children living with ASD strongly represent the manifestation of their community and cultural beliefs, and their understanding and support of the disorder. Thus, it is essential that the voice of the Xhosa-speaking parents, non-Westerners, are heard and integrated into Western ideals of the management of ASD in the South African context.

1.4 Research Questions

The study was guided by the following primary research question: How do Xhosa-speaking parents experience caring for their child with autism spectrum disorder in their community?

To gain richer insight, the following secondary questions were explored:

i. What are Xhosa-speaking parents' perspectives of ASD?
ii. What is their daily experience of the diagnosis?
iii. How do the Xhosa-speaking parents experience the knowledge and misconceptions (if any) of ASD in the community?
iv. What are the Xhosa-speaking parents' experience of support and understanding in the community?

1.5 Research Aims

The primary aim of this study was to explore and better understand Xhosa-speaking parents' experiences and perceptions in caring for their children with ASD. The second aim was to consider the possible influence the community's beliefs have on the outcome of management and support of the manifestation of ASD.

Secondary to the above-mentioned goals is the promotion and education of the community about ASD and the reality of the benefits of early intervention; thus, empowering Xhosa-speaking parents to identify ASD better early on in the child's development to prevent any

further developmental delays and seek help from professionals. In turn, this could reduce any social stigma related to a family and child with ASD and could improve levels of support in the family and community. Ultimately, the acceptance of ASD in Xhosa-speaking families could extend to a shared acceptance in the community.

1.6 Theoretical Framework

For a child with ASD to live an optimal and functional life, one needs to gain better understanding of the child and his or her context, as well as the constant interplay between these two. Understanding the influences that interact, especially those that hinder children's capacity to develop age-appropriately and reach their full potential, is essential for support interventions.

According to Ravindran and Myers (2012), the way others perceive a disability like ASD is not only based on the extent of functioning, but also conceptualised and influenced by contextual factors such as "family attitudes, financial resources, adaptations in the physical environment, legislation to support individuals with disability and the prejudice of society" (p. 312). Bronfenbrenner's bioecological model provides a framework to dissect every sphere of the child's development and provide in-depth understanding of the implications that the context and its interactions have for the child, in this case the outcome and treatment of ASD.

Even though the bioecological approach stems from a Western perspective, it assimilates aspects of the African perspective that the child "coexists with the community" (Berry et al., 2002a, p. 106). Botha and Moletsane (2012) reiterate this point by explaining that Africans hold the idea that "a person exists because of other people", showing the importance that the African culture attaches to the vital role of relationships, interactions and the context, and the interplay between these (p. 70). Another African belief that is coherent with the ecological perspective is the importance of maintaining an equilibrium within the systems, and that if there is a disturbance in one of the systems, it affects the others and ultimately the well-being of the child (Donald et al., 2016; Viljoen H., 2003). The integration of these indigenous African beliefs with the bioecological framework creates the coherent perspective that the environment in

which the child lives, as well as the processes the child experiences directly or distantly, could inhibit or increase his or her potential and functioning (Swart & Pettipher, 2016).

Bronfenbrenner outlined four important, interacting processes that need to be examined to understand the development of children in their context better: *proximal processes, person characteristics, the context,* and *time* (Bronfenbrenner & Morris, 2007). These will be discussed in depth in Chapter 2 to understand the experiences of parents who care for their children with ASD in the Xhosa-speaking community better.

1.7 Research Methodology

The table on the next page serves to summarise the research process and methodological decisions made for the study briefly. The research methodology will be discussed comprehensively in Chapter 3.

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❖ Visual artefact/art activity to mediate discussions: "River of Life" drawing</td><td>Inductive, thematic analysis of data derived from the interviews and 'River of Life' drawing</td></tr>
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Table 1.1

Summary of Research Methodology

1.8 Clarification of Concepts

The subheadings will be listed in alphabetical order.

1.8.1 Autism spectrum disorder

The term *autism spectrum disorder (ASD)* is known as a neurodevelopmental disorder that displays specific behaviours that impede the person's daily functioning at an early age (Lord et al., 2018; Mthombeni & Nwoye, 2018). Presently, it is understood to be measured on a continuum that varies from mild to severe behaviour (Lauritsen, 2013). According to the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, an ASD diagnosis is based on two main indicators: "persistent deficits in social communication and social interaction across multiple contexts", and "restricted, repetitive patterns of behavior, interests or activities" (American Psychiatric Association, 2013). Requirements of the DSM-5 need to be met to make a formal diagnosis.

1.8.2 Caring

Care can be defined as looking after the child and satisfying the child's basic needs so that the child feels protected and not vulnerable. According to Maslow (1943), if the need of the child is met continuously, he or she will develop healthily (physically, socially, and emotionally), but if this process is not met, it can endorse the child's vulnerability and poor development. This can be influenced by the environment, the actions, thoughts, and feelings expressed in the parent's relationship with the child. In this study, caring refers to the responsibility of the parents of the child diagnosed with ASD in meeting the needs of the child.

1.8.3 Child

For this study, a child can be regarded as the son or daughter of the parents and between the ages of 3 and 17 who are dependent on their parents for their basic needs and development.

1.8.4 Parent

In this study, *parent* refers to the child's main caregiver who is responsible for meeting the needs of the child that has been diagnosed with ASD. This formed part of the inclusion criteria for selection of participants for the study. The parents directly influence the child's experience of the social setting, relationships, and support (Viljoen et al., 2019)**.** They are the sole providers and oversee decisions made on their behalf, especially regarding intervention. The parent can represent a biological mother, biological father, stepmother, stepfather, older sister, older brother, grandparents, or foster parents.

1.8.5 Xhosa-speaking community

The selected Xhosa-speaking community is a small representation of the Xhosa population in the Western Cape, situated in Cape Town. They communicate in Xhosa and some also in English. All the participants grew up being exposed to indigenous African beliefs.

1.9 Outline of Chapters

Chapter 1 introduced the concept of ASD, especially in the African, non-Western context. It discussed the important role of parents in the community and their understanding of ASD for early intervention and support. My personal rationale for the study was shared, and the problem statement, the research questions, secondary questions, and the aims of the study were outlined. The theoretical lens of Bronfenbrenner's bioecological model was explained, and the methodological decisions were shared. Lastly, the ethical dilemmas that the study could be confronted with were considered.

Chapter 2 discusses various perspectives and ideas in literature related to ASD, parents or caregivers and the child-parent relationship, the African culture and context, as well as the theoretical framework of the study.

Chapter 3 revises the research paradigm, design, and methodology, information about the participants, and data collection and analysis, but in greater detail.

Chapter 4 aims to present the findings of the research study. It outlines and discusses the themes found from the analysis of the data.

Chapter 5, the final chapter, presents the reader with an interpretation of the findings and suggests recommendations for further research.

1.10 Conclusion

The purpose of the study was to contribute to the identified gap in research for a more African, non-Western approach to understanding ASD specifically from the perspective of the parents. It aimed to consider one specific representative of the African population, the Xhosa-speaking community, and learn from their experiences and understanding of the existence and functioning of ASD in their own children.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

Individuals living with ASD are considered a vulnerable population (Fisher et al., 2013; Jawaid et al., 2012; Moreno et al., 2017) as they struggle with communication and language, and engaging in social activities (American Psychiatric Association, 2013; Wing, 2002). Jawaid et al. (2012) believes it is the characteristic of ASD that especially makes them more susceptible to different forms of abuse and neglect from peers, family, and their community. In Fisher et al.'s (2013) research, it was found that people with ASD, specifically, were more likely to be targeted and experienced forms of bullying and abuse. A cross-sectional study in 2005 revealed statistics that were more specific, indicating that 16.6% of people living with ASD had been vulnerable to sexual abuse, and 18,5% had been vulnerable to physical abuse (Mandell & Novak, 2005). Mandell and Novak (2005) elaborate by adding some of the implications of the abuse and mention feelings of possible rejection, loneliness, insecurity, development of a low self-image, and low moods.

The feeling of loneliness has been noticed particularly among children living with ASD (Bauminger et al., 2003). Barrio et al. (2018) add that children with ASD also have difficulties with belonging in their cultural and ethnic context, which contributes to the complexity of the experience. They warn that misunderstandings of the culture and its practices could lead to more feelings of rejection and ineffective treatment. The difficulties with communicating and socialising make people living with ASD more vulnerable to abuse, and Jawaid et al. (2012) note how it may prevent them from achieving "occupational functionality" (p. 342). In a study completed by Hofvander et al. (2009), it was found that more than half of the people with ASD were unemployed or were on medical leave (as cited in Jawaid et al., 2012).

In contemplation of alleviating this course of victimisation and inducive isolation, it is important to understand how ASD is perceived in specific communities to prevent

misunderstandings and a delay in or lack of support. In each community lies a culture, their own ideas, and a way of living that are shared. This needs to be portrayed to the rest of society, specifically health professionals, with the goal of understanding and accepting. Ravindran and Myers (2012) believe it becomes the professional's responsibility to be culturally aware and sensitive, to contribute effectively to the prevention of misunderstanding and pain in the communities.

Although an abundance of research on the perspectives of Western- and European-based communities exists, researchers only recently have begun to delve deeper into understanding ASD in an African context (Franz et al., 2017; Mthombeni & Nwoye, 2018; Nasiorowska, 2015; Viljoen et al., 2019). Owing to the diverse population of South Africa, research specific to the African cultures and communities has been limited, especially in the Xhosa-speaking culture.

Therefore, the primary aim of this study was to delve deeper into the reality of the experiences of parents caring for their children living with ASD in the Xhosa-speaking community. The secondary aim was to emphasise the role that parents play in the realms of diagnosis, management, and support in their children's growth, and to highlight the effects ASD has on the parents and their family in their community.

The next section is devoted to the theoretical framework of the study, namely the bioecological model. The theoretical framework was utilised not only in analysing and understanding the data but also to make sense of the context of the study, namely Xhosa-speaking parents and communities, as well as the functioning of parents caring for children with ASD in these communities. The suitability of the model and how it assimilates aspects of the African perspective was motivated in Chapter 1, Section 1.6. Next, the *process, person, context,* and *time* characteristics that the model implies are discussed in detail.

2.2 Theoretical Framework: Bioecological Model (PPCT)

According to Bronfenbrenner and Morris (2007), the model has both objective and subjective properties. The objective properties constitute what is already there, the established constructs of the context that interact with the subjective properties that are experienced personally by the active role players in that environment (Bronfenbrenner & Morris, 2007). In this study specifically, it would be the experiences of the parents and the child living with ASD, the subjective property; in a Xhosa-speaking community, family, and society, the objective property. These properties are both symbiotic and influence one another (Bronfenbrenner & Morris, 2007). Thus, the parents' perceptions and their engagement with their context play an important role in shaping the child with ASD and the child's future.

Four dimensions to be aware of are in constant and reciprocal interaction with one another, equally playing a role in forming, changing, and developing the person, in this case the child with ASD and the Xhosa-speaking parent (Bronfenbrenner & Morris, 2007). In this way, as stated before, the theoretical framework provides a lens to make sense of the phenomenon of caring for a child with ASD in the Xhosa-speaking community. These dimensions are *process* factors, *person* factors*, contexts,* and *time*.

Of the four dimensions, the p*rocess* factors are regarded as the most important function contributing towards human development (Donald et al., 2016). Bronfenbrenner and Evans (2000) use the term "engines of development" to emphasise its importance. *Proximal processes* can be understood as the different forms of interaction that occur between the "person and the environment" over a consistent period (Swart & Pettipher, 2016, p. 12). For this study, the interactions between the Xhosa-speaking parent and child with ASD, as well as their interaction with(in) their community over a period of time, were relevant.

In 2000, Bronfenbrenner and Evans expanded the theory by elaborating on the importance of the 'exposure' of the interaction between the developing person and the *proximal processes*. They divided 'exposure' into five dimensions: *duration, frequency, interruption, timing,* and *intensity*.

The *duration* of the interaction can be described as the length of exposure; for example, the length of time parents engage in some kind of intervention or support for their child. *Frequency* is understood as the number of times that the interaction occurs. Does the child/parent receive support consistently, or is it interrupted? The *timing* of the interaction focuses on the important role of when, at what time during the child's life, the parent was present or absent, and responsive or unresponsive to the child's needs, or the timing of the support and/or early diagnosis (Bronfenbrenner & Evans, 2000). In the study, it was crucial to examine the timing of amicable interventions and support to determine how effective it is and/or might be for other individuals that align with African (non-Western) views (Bronfenbrenner & Evans, 2000).

The *intensity* of the interaction can be described as the "strength of the exposure" (Bronfenbrenner & Evans, 2000, p. 118). This is reliant on the consistency or inconsistency of the interaction; for example, the support or understanding from the parent and how much is given consistently (Bronfenbrenner & Evans, 2000). This dependable relationship between the parent and child with ASD affects the extent to which a child with autism or a parent progresses emotionally, behaviourally, and how easily they can adapt and be integrated into the community. Although p*roximal processes* play a vital role, the degree of power it holds and the direction it takes are dependent on the varying characteristics that a person may possess and/or might develop. Integrated into the parents are their *person* factors, beliefs, and culture that need to be considered.

The *person* characteristics encompass the "biopsychological characteristics" of the person; in this case, the child with ASD or the parent caring for the child with ASD. This involves biologically inherited traits as well as learnt or experienced features personal to the developing child and parent (Donald et al., 2016, p. 45). Bronfenbrenner and Morris (2007) define the essence of the *person* by dividing it into three characteristics: *demand, resource,* and *force characteristics*. The characteristics of the parents are helpful in understanding the extent of the influence they may have in determining the intensity of the *proximal process* or

the parent/child relationship, which could affect the way in which the risk or protective factors of the child with ASD manifest.

Demand characteristics can be explained as obvious factors that immediately identify a person, like age, gender, race, and physical appearance of the child and/or parent (Tudge et al., 2009). An example of this could be that a child with ASD looks like any typical peer when only their physical appearance is considered. This possibly involves the discouragement or acceptance of various reactions and expectations from their community, that either inhibits through stigmatism, or encourages efficient functioning of the child and the parent (Bronfenbrenner & Morris, 2007).

Resource characteristics can be related to ability resources; for example, intelligence, experiences, knowledge, or skills, and also "social and material resources" like food, housing, educational needs, and caring parents (Tudge et al., 2009, p. 200; Bronfenbrenner & Morris, 2007). The *resource* characteristics can assist in determining how much support parents access, and how much they still need, and to what extent the child could be rejected or accepted by the Xhosa-speaking parent and community. In this study, children with ASD and their social resources of having parents who care for them was explored closely, as well as the possible influences of these *persons'* characteristics on their development.

Lastly, *force* characteristics are associated with the person's mind and character; for example, temperament and motivation (Tudge et al., 2009). This can contribute to the continuity or discontinuity of *processes* that take place in the parent and child's *context*, essentially affecting their development and route of support (Bronfenbrenner & Morris, 2007). The *force* characteristics needed to be considered for the study so that the protective factors, like resilience and coping strategies, could provide insight into the experience of the parents caring for their children living with ASD. *Proximal processes* rely on the functioning and predispositions of the parent and child's current and secondary environments (Bronfenbrenner & Morris, 2007).

The *context* in which a person exists is the third dimension of the model and is constituted of four interrelated systems that all influence the development and support of the parent and the child with ASD. These are the *microsystem, mesosystem, exosystem and macrosystem* (Berry et al., 2002; Bronfenbrenner & Morris, 2007; Donald et al., 2016; Rogoff, 2003; Swart & Pettipher, 2016; Tudge et al., 2009). Steinberg (1995), as cited in Bronfenbrenner and Morris (2007, p. 817) comments on the important role that the person's *context* plays in shaping the *processes* that occur: "No process occurs outside of a context. And if we want to understand context, we need to take it into account, not pretend to control it away". This study chose to focus on exploring the influence of the Xhosa-speaking community context and the effects of its *processes* or interaction on parents caring for their children with ASD.

The m*icrosystem* can be described as the person's "immediate experiences", where they are influenced directly by the people with whom and activities with which they spend most of their time (Rogoff, 2003; Tudge et al., 2009, p. 47). These proximal interactions foster the development of emotional, moral, physical, cognitive, and spiritual growth (Donald et al., 2016). In order to completely understand children's experiences, one needs to analyse the relationships in which the children are directly involved; for example, the parents (Brendtro, 2006). The parents' understanding of their child's disorder, its origin, and what the most effective interventions seem to be, influence the active participation of the child with regard to resources, activities, and early intervention (Ravindran & Myers, 2012).

The *mesosystem* involves the continuous interaction between two or more *microsystems,* which ultimately affect the functioning of the child with ASD or the parent; for example, the family's support network, like teachers, extended family members, neighbours, health professionals, and so forth (Donald et al., 2016; Rogoff, 2003). They can influence the parents' view and rejection or acceptance of ASD directly, thereby influencing the child (Ravindran & Myers, 2012).

The *exosystem* involves a system that indirectly influences the person through the relationships he or she has with those in the *microsystem,* for example, the parent's work

environment and working relationship with helping professionals (Donald et al., 2016; Tudge et al., 2009). The collaborative relationship between the parents and professionals, both holding their own cultural beliefs, alongside the amount of power that professionals can hold, could delay, or ignite diagnosis (Ravindran & Myers, 2012). Professionals' understanding of their clients' beliefs and the way their community functions could ultimately affect the effectiveness of the communication and treatment plan.

Embedded in this 'circle of influence' is the family's sociohistorical context, involving the parents' friends and community – with its hidden ideals and cultural values. The *macrosystem* represents the larger cultural, economic, and social setting that contains overarching beliefs, values, and ways of living. The last system, can be understood as "influencing (and being influenced by) all of the other systems" (Tudge et al., 2009, p. 201), which in turn can cause changes in the child's behaviour and development, as well as the Xhosa-speaking parents' care for their children with ASD (Rogoff, 2003).

Briefly stated, the process of meaning-making, which determines the parents' understanding of ASD (Ferguson, 2002), is ultimately shaped by their cultural ideals and societal principles, which include the economic, political and spiritual dimensions (Ravindran & Myers, 2012). Parents' personal experiences, the way in which they were brought up by their parents, the parents' attitudes, their personality, and/or one could say, their potential for resilience (*person* factor), all come into play (Hebert & Koulouglioti, 2010).

Rogoff (2003) adds an important argument, namely that while there is a continuous process of participation in cultural activities, persons and their cultural community across groups of people adjust and change. This is important to consider when exploring the Xhosa-speaking culture and their ways of living. It shows that the culture does not remain static and that the Xhosa-speaking parents could have varying degrees of experience in caring for their children with ASD. They might not adopt the beliefs of their family members or community.

Super and Harkness (1997) agree that it is vital to consider the developmental or ecological niche that is unique to the person (as cited in Berry et al., 2002). The developmental

niche on which the study focused consisted of the Xhosa-speaking community, African cultural norms and beliefs, gender roles, children's upbringing in a Xhosa-cultured context, as well as parents who care for a child with ASD. When considering the child's developmental niche in the study, three factors were included: the physical and social settings of the parent with a child with ASD, the customs of child care that the parent adopts, and the parent's mental state and beliefs about parenting (as cited in Berry et al., 2002). These factors contributed to understanding the influences on the parents and guided analysis in the study.

The fourth and last dimension in Bronfenbrenner's PPCT model is consummated with the element of *time.* The *proximal processes* rely on time periods and are contingent upon the frequency and non-frequency of the *processes* (Bronfenbrenner & Morris, 2007). Although it is stated last, it is an all-encompassing concept that affects every aspect of development and *process* occurring in and across systems. This concept was analysed and divided into three levels: *micro-time, meso-time,* and *macro-time*. Bronfenbrenner and Morris (2007) understand *micro-time* to be "what occurs in the course of an interaction or activity" (as cited in Donald et al., 2016, p. 46), and the outcome is dependable on the continuity or discontinuity of the *process* (Bronfenbrenner & Morris, 2007). For example, the receiving of continuous support would be the ideal scenario for a child with ASD.

Meso-time reflects the consistency of these activities or interactions over a period; for example, a parent may receive support by finding a diagnosis for their child, and afterwards may decide to stop the intervention process (Donald et al., 2016). This could be a risk factor for the child's development and future. The *macro-time* represents the historical period, as well as "changing events and expectations in larger society"; for example, the effects of the COVID-19 pandemic we are currently facing, or the changing ideas across cultures (Bronfenbrenner & Morris, 2007, p. 796).

The element of *time* is included in helping us explore the experiences of Xhosa-speaking parents. It gives ideas about the age of the parent, the time at which the parent received or did not receive support, the age of the child when he or she received help, and the duration of

the support from organisations in the community to other people and family members. All of these influence the experience of parents and provide insight into the application of their beliefs and way of functioning.

In 1989, Bronfenbrenner summarised the concept of the PPCT model by explaining that all its factors function holistically to cause small and big adaptations in the person's development:

> In order to develop—intellectually, emotionally, socially, and morally—a child requires, for all of them, the same thing: participation in progressively more complex reciprocal activity, on a regular basis over extended periods of time with one or more other persons with whom the child develops a strong, mutual, irrational attachment, and who are committed to that child's development, preferably for life. (Bronfenbrenner & Morris, 2007, p. 816).

In the above-mentioned summary, he also emphasises the vital role that parents play in their children's development. In a review about parents' understanding of their children's ASD, it was found that their own beliefs significantly affected the support provided for their child (Hebert & Koulouglioti, 2010). To delve deeper into this aspect, it is necessary to explore the understanding and beliefs parents hold about ASD. The exploration of parent's perceptions and experiences contributes immensely to providing support for children with ASD, and that which ultimately leads to a functioning family and community.

In conclusion, Bronfenbrenner's bioecological model provides us with a way of understanding the many components that play a role in contributing to the experience of parents caring for their children with ASD. In the next section, the reality of the emerging disorder, ASD, and its "so-called" universal traits, which can be categorised under Bronfenbrenner's *person* characteristics in the *microsystem*, will be discussed. The universal traits should extend over various contexts (systems) and needs to be relevant to the parent and child's developmental niche.

2.3 Autism Spectrum Disorder (ASD) as Evolving Disorder

Next, the prevalence of ASD globally and locally will be explored, followed by a description of the nature of ASD based on the Western construct, as well as a discussion of the challenge of diagnosing ASD.

2.3.1 Prevalence

In a global study by Elsabbagh et al. (2012), an estimate of the prevalence of ASD was provided: 62 out of 10 000 (0.62%) people. Along with this, another study in 2012 suggested that 1-1.5% of the global population were diagnosed with ASD (Chambers et al., 2017). With most of the research being performed in the USA and European countries, the World Health Organization (WHO) (2013) describes the burden of ASD affecting 7.6 million 'Disability-Adjusted Life Years' (DALYs). Disability-Adjusted Life Years can be understood as the loss of one or more healthy years of living due to disability, death, or being ill (Indicator Metadata Registry Details, 2021). This roughly forms 0.3% of the global burden of disease (as cited in Guler et al., 2017).

The Centre for Disease Control and Prevention, which is based in the USA, recently performed extensive work monitoring the prevalence rate of children with ASD. In 2016, they found that 1 in 54 children or 18.5 per 1 000 presented with ASD. They also found that 'black' children, in comparison with 'white' children with ASD, were less likely to have an initial assessment and diagnosis by the age of 3. It was concluded that rates have risen since 2014 (Maenner, et al., 2020).

Although there is more insight into the prevalence of ASD in other countries, which are likely to be of higher income, exact prevalence levels in South Africa are unknown (Franz et al., 2017). Pillay et al. (2020) attempted to make a prediction and, considering children under the age of 15, realised that with an estimated 1% prevalence rate, 169 286 children could have ASD.

When narrowed down to the Western Cape, it was found that of the children attending schools, 940 children were identified as living with ASD, which made up 0.08% of the school population (Pillay et al., 2020). According to Guler et al. (2017), in 2013, more than 500 children with ASD were on the waiting list in the Western Cape for special education services, which at the time led to about a three-year waiting period for a child to be placed at a school that catered for children living with ASD. Pillay et al. (2020) state that according to school statistics, there was an increase of 76.03% in identification of ASD in schools between the years 2012 and 2016.

The closest we can get to grasping the lack of research in South Africa is through Franz et al.'s (2017) comprehensive scoping review of sub-Saharan Africa (SSA). Of a total of 24 467 online publications about ASD, only 120 came from SSA. Of these publications, 79% originated from South Africa and Nigeria. This shows that there is a huge disparity between the research performed in the Western parts of the world than in the African and indigenous areas. It poses a challenge with the increase in ASD cases in South Africa and the growing need for appropriate intervention, support, and understanding of the manifestations of ASD in our multicultural communities. This has the potential to make the community more vulnerable and unprotected and to create isolation in the community and society (Fisher et al., 2013; Jawaid et al., 2012; Moreno et al., 2017).

Before exploring indigenous African views to help understanding ASD in these communities better, it is important to consider more closely how ASD can be defined and identified as more of a Western construct. Researchers believe that by exploring this, discrepancies and similarities can be identified that could shed light on parents' experiences of ASD and whether it is the same across cultures and in communities (Berry et al., 2002a; Wing, 2002).

Lotter (1978) was one of the first researchers to investigate if common experiences were shared in a different culture, like Africa. He used the same criteria and procedures used in England to identify similar behaviours that children with ASD showed (Lotter, 1978). Although

Lotter's conclusions may have had many limitations, he provided evidence that they shared similar experiences with regard to ASD (Lotter, 1978). He also provided guidelines and recommended that further research be explored by people who are familiar with the culture and group's beliefs and ideas (Lotter, 1978). He seemed reluctant to limit or hinder the authenticity of the research by imposing his own ideals and beliefs on their experiences. Lotter played an important role in bridging the idea that autism could have marked features and characteristics that could be applied across different contexts.

The next section will discuss the nature of ASD as a Western construct, using the triad of impairments described by Wing (2002) and integrating the DSM-V (2013) criteria.

2.3.2 The nature of ASD

Early in the 20th century, Eugen Bleuler, a psychiatrist who coined the term *autism,* seemed to grasp the essence of its manifestation (Maye et al., 2017). The term was taken from the Greek word *autos* meaning *self* and further developed to mean "isolated self", which can be described as "rejecting reality" and withdrawing into one self (Maye et al., 2017, p. 2).

Lorna Wing and Judith Gould described the nature of autism as consisting of a triad of impairments: "the absence or impairment of social interaction, communication, and development of imagination," and in addition, a recognisable feature of "narrow, rigid, and repetitive patterns of activities and interests (RRBI)" (Wing, 2002, p. 11). In relation to the triad of impairments, the DSM-5 narrowed down the impairments into two diagnostic criteria, namely *impaired social interaction*, which includes communication, and *restricted behaviour*, both of which need to be met by clinicians for diagnosis (refer to Appendix A) (American Psychiatric Association, 2013; Maye et al., 2016; Wing et al., 2011). Sensory difficulties were included in the second list of diagnostic criteria.

2.3.2.1 Social Interaction

Uta Frith (as cited in Bishop, 2008), a developmental psychologist, became a pioneer in initiating research based on a more neurobiological approach of autism. She provided

evidence of a deficit believed to be a core feature of autism and that had an implicit influence on the conceptualisation of autism: theory of mind (Bishop, 2008). Theory of mind can be defined as the "cognitive capacity to understand that others may have beliefs, desires or intentions that differ from one's own" (Bishop, 2008, p. 19). In other words, people living with ASD find it difficult to sense other people's thoughts and feelings, which impedes their ability to empathise and connect with others (Wing, 2002). This concept is important to mention because it helps to understand the reason for social impairment in ASD.

2.3.2.2 Communication

Communication is very dependent on a person's language ability and comprehension**,** which includes using and understanding speech, intonation, controlling one's voice, as well as using and understanding non-verbal communication (Wing, 2002). It is common for children with ASD to have either delayed or abnormal speech, such as echolalia where the child repeats words without attaching any meaning to them and lacks conversational skills (Wing, 2002). Volkmar and McPortland (2014) reported that most parents in South Africa have mentioned echolalia as a tell-tale sign of ASD (as cited in Mthombeni & Nwoye, 2018).

Children living with ASD are also not able to comprehend what is spoken, especially when the message relates to familiar aspects in a certain context. As Wing (2002) states, there seems to be a "lack of flexibility in word meaning" (p. 24). In addition, language that verges on abstract phrases or ideas are interpreted poorly and could be taken literally. Lastly, a child with ASD may have inappropriate intonation and volume, which sounds monotonous or robot-like, or may mimic sounds or other people (Wing, 2002).

2.3.2.3 Imagination

According to the Merriam-Webster Dictionary (2020), imagination is defined as "the act or power of forming a mental image of something not present to the senses or never before wholly perceived in reality" (*Definition of IMAGINATION*, 2019). Children with autism tend to not develop their imagination, and thus struggle to pretend play and engage in imaginative

activities (Wing, 2002). This also refers to their limitations in understanding people's feelings and utilising and integrating past and present experiences in order to change, adapt, or plan (Wing, 2002).

2.3.2.4 Repetitive and Restricted Behaviours or Interests

Owing to a limited imagination and understanding of people, children with ASD find pleasure in repeating activities that they are capable of doing (Wing, 2002). In relation to the sensory difficulties referred to in the DSM-5, repetitive sensations are a common feature of children with ASD - they use tasting, touching, feeling, sight and/or sounds to aid their need for sensory stimulation (Wing, 2002). As described by Hazen et al. (2014), sensory behaviours can be categorised into three common impairments: sensory overresponsiveness, sensory underresponsiveness, and sensory-seeking behaviour. *Sensory overresponsiveness* occurs when the child reacts negatively to sensory stimuli and tends to avoid it. *Sensory underreactivity* occurs when the child seems to have no reaction or a delayed reaction to expected sensory input. *Sensory-seeking* behaviour occurs when the child constantly desires to engage in activities with sensory stimuli (Maye et al., 2017).

Some children with ASD engage in "elaborate repetitive routines" that may not be interrupted or altered in any way, as they cause distress for the child (Wing, 2002, p. 28). Many of the common stereotypic behaviour found was "rocking/swaying, unrecognisable vocalisations, and hand flapping/waving" (Maye et al., 2017, p. 8). It is typical for a child with ASD to insist on sameness and have inflexible thinking patterns, which ends in poor social skills and behavioural difficulties (Maye et al., 2017). They are also known to have extremely limited interests that may or may not have any specific purpose, and may pay attention to that interest only (Maye et al., 2017).

The DSM-5 states that the implicit or explicit behaviours need to be persistent and limit the child's daily functioning (American Psychiatric Association, 2013). An inhibition to engage in social communication and interaction naturally, as well as the presence of restricted,

repetitive patterns of behaviour, interests, or activities provides us with a better understanding of their challenges (American Psychiatric Association, 2013).

In saying this, it is important to note that the information regarding the understanding of autism has been defined by Western contexts and Western discoveries and is at risk of being "culture bound" (Berry et al., 2002b, p. 332).

Although this poses a problem in the African context and in the Xhosa culture, it is the only framework to work from that is backed by a history of developing research as far back as 1943. Therefore, the ideal goal is to find "culture-common aspects of psychological functioning" that can be applied to various contexts (Berry et al., 2002b, p. 332). Wing (2002), a mother of a child who lived with autism and a well-renowned psychiatrist who contributed to the development of knowledge about autism, seems to support the idea that there are common features about autism to which all cultures can relate. She states that "children and adults with autistic disorders have the same basic patterns of behaviour wherever they live. When parents from different cultures meet, cultural barriers melt away and common experiences are shared" (Wing, 2002, p. 2).

Therefore, making a diagnosis poses various difficulties. The next section is devoted to exploring this.

2.3.3 The challenges of diagnosis

Although it seems possible to identify features of ASD across platforms, there are challenges when it comes to formally diagnosing a child with ASD. ASD is regarded as a neurodevelopmental disorder that appears in the early stages of development (Maye et al., 2016). Yet, the behaviour associated with the disorder may become explicit to others only once the child/young adult is confronted with societal expectations, especially with interpersonal relations (Maye et al., 2016). This could mean that it could be diagnosed at a later stage and not only during the initial three years of development. Maye et al. (2016)

emphasises that every person with autism is unique and presents with varying behaviour, intelligences, and impairments, which makes the diagnoses complex.

One of the challenges in the realm of ASD is how difficult it can be to diagnose a person with ASD. Contributing to this difficulty is that ASD is presented on a broad continuum that can range from mild to severe manifestation of symptoms and explicit behaviour (Lauritsen, 2013). It assists in indicating the amount of support required for a person as well as possibilities of co-morbid conditions (American Psychiatric Association, 2013; Wing, 2002). The continuum tends to pose a problem, making it tough to specify and/or clarify the type of ASD and how the behaviour is exhibited. Furthermore, Wing (2002) argues a few more reasons that may make the diagnostic process problematic.

Many of the related impairments can exhibit in various ways, with some of the signs being inapparent: ASD is not specific to a person's general intelligence – it can range from low to high intelligence, and it can co-occur with other physical, psychiatric, and developmental disorders. Therefore, it can cause some confusion about the accuracy of the disorder. As the child develops and gets older, the behaviour patterns may alter, as well as the environment and/or the person with whom the child lives. In addition, the influence of education in the child's life can affect his or her behaviour, and the child's personality and upbringing will also influence his or her behaviour (Wing, 2002).

Pachter and Harwood (as cited in Mandell & Novak, 2005) state that "cultural factors are intertwined with thoughts and behaviours" and this may contribute to the way that "families address deviations in their children's development" (p. 110). Stone-Macdonald & Cousik (2017) conclude that "autism is truly a spectrum disorder, not just in the level of severity, but also in the symptoms that are most commonly observed in different cultures" (p. 96).

Therefore, it is a challenge to make a true diagnosis, as all these differentiating factors need to be considered, especially in a context where the community have little to no access to health care and a limited understanding of and exposure to ASD, and where they are unfamiliar with the necessities of the development of social communication (Chambers, et al.,

2017). Additionally, the diagnosis does not guarantee the support of the country's services and a capacity to understand the influence and direct effect it will have on the parents and their family (Stone-Macdonald & Cousik, 2017). Therefore, the diagnostic criteria should be only a guide for diagnosis. Although there are limitations to the diagnosis process, a formal diagnosis would need to be made according to the criteria in the DSM-V and ICD-10 (see Appendix A).

Lauritsen (2013) challenges the reliability of the diagnostic criteria, which seem to have explored the manifestations of the diagnosis across various countries and cultural backgrounds only narrowly, and in addition, have had very few discussions with various clinicians from various backgrounds. This highlights how certain countries, like South Africa, are being underrepresented and underresearched. Only with difficulty can a child be identified as ASD, due to the limitations in training, the absence of standardised assessment tools, and most importantly, the understanding of various cultures of the manifestation of symptoms (Stone-Macdonald & Cousik, 2017). Despite the above-mentioned variations in ASD, there are common impairments that continue to be present (Wing, 2002).

The common characteristics of social interaction, communication, imagination, and repetitive and restricted behaviour were explored, as well as the difficulty of diagnosing. However, it is important to note that the variations in behaviour manifestation and/ or support are conducive to the type of environment (context) in which they grow up and the person's characteristics. Bronfenbrenner's context dimension, specifically the *macrosystem*, will be discussed next to emphasise the importance of culture.

2.3.4 The importance of culture

There seemed to be limited research exploring the understanding of ASD prior to the year 2002, specifically in a cultural context (Daley, 2002). Questions asked were: (i) Does culture impact on the biological condition of ASD? (ii) How does culture influence the manifestation of ASD? (iii) What effect does socialisation and cultural interactions have on the interpretation and understanding of ASD? (Daley, 2002). Since 2002, more researchers started studying the

effects of culture on the interpretation of ASD. However, research based on analysing the developing interventions and assessment for diagnosis across diverse cultural contexts is still limited (Barrio et al., 2018).

In trying to understand how diverse cultural contexts affect the behaviour of children with ASD, cross-cultural psychology as a scientific field can be explored (Berry et al., 2002). This field of psychology is important, as it assimilates with the human developmental concepts that Bronfenbrenner held. A child with ASD, in a specific cultural context, cannot be viewed without considering the child or parent and their relationship in the particular context (Bronfenbrenner, 2006).

Rogoff (2003) defines culture as “not static; it is formed from the efforts of people working together, using, and adapting material and symbolic tools provided by predecessors and in the process creating new ones” (p. 51). Rogoff’s view aligns with the perspective that this study regards as meaningful.

Firstly, culture is seen as being influenced by past behaviour, and additionally plays the role of creating future behaviour. Rogoff (2003) succinctly summarises the idea when he states that individuals develop as members of cultural communities. This means that we can understand aspects of persons’ development through their being and their involvement in their cultural practices. It also points to the dispositions of the community, but understands that these factors could change (Rogoff, 2003). Secondly, it is important to note that this is a continuous process that can be confronted with change and diversity or remain in a monotonous state in the social environment over time (Segall et al., 1999).

We can relate these ideas to how Bronfenbrenner integrates both the macrosystem that encompasses cultural beliefs, and the chronosystem that is affected by past events. In turn, this links to the micro- and mesosystem, specifically the practices of the people involved in their context. The processes that take place in a consistent or inconsistent manner, for example the parents’ interactions with their cultural beliefs and actions, play a meaningful and

active, or passive, nonreactive role in their relationship with their child. This is also dependent on the dispositions, demands, and resources of that person, parent, and child.

In every culture, each person has a unique childhood experience, expected goals of individuation, and milestones or competencies for development that need to be considered (Grinker et al., 2012). Collectively, the community have implicit ideas of what and how they believe the person needs to develop, and thus, this becomes their norm. Rogoff (2003) supports this notion by saying that “goals of human development vary considerably according to the cultural traditions and circumstances of different communities” (p. 18). Ultimately, these factors give us an idea of children living with ASD and their development. The model allows us more specifically to understand the effects culture could have on early diagnosis and understanding the diagnosis, as well as courses and ideas about treatment.

Moreover, it has been suggested by the International Classification of Functioning-Child Youth (ICF-CY) that in order for ASD to be managed efficiently and successfully, the person’s context, including cultural and attitudinal factors, needs to be analysed, thus adopting a holistic approach (Bölte, et al., 2018). The ICF prospect also considers the effects of the context on the person, and thus can focus on creating new strategies and interventions that reach people’s potential functioning in their context (Bölte, et al., 2018). In accordance with the ICF, Ravindran and Myers (2012) emphasise the extent to which one’s culture can decide the treatment process, treatment methods, resources available, and relationship with family and professionals.

To support the above-mentioned information, it is important in this study to review community-based research projects completed together in South Korea and South Africa, where ASD is underdiagnosed. These two communities have in common that they have limited services available, and both create their own cultural meanings of developmental disorders (Grinker et al., 2012). In each community it was found that they shared ideas and practices in their culture that informed their way of thinking and meaning-making of ASD (Grinker et al., 2012). It is important to explore and consider how management of ASD influenced their

experience of ASD. This shows what support is needed and what support existed, and lastly, how the community accepts or rejects ASD (Grinker et al., 2012).

Grinker's et al.'s (2012) study intended to emphasise the voice of the local community. The first goal was to assist in the process of analysing the interaction between ASD and culture and bridge the gap of successful community engagement. The second goal was to enhance support in communities that have been disregarded in the research field in the past. This is similar to the African communities that seem to have been forgotten.

2.4 A Glance into the African Culture

> *"I am because we are, and since we are, therefore I am" writes John Mbiti (1990, cited in Berry et al., 2002a, p. 106).*
>
> *"I feel, I dance the Other; I am" writes Senghor (1964, cited in Berry et al., 2002a, p. 73).*

The above-mentioned quotes encompass the essence of understanding the root of African culture and community. For Botha and Moletsane (2012), it emphasises the idea of a person existing because of others. However, Nsamenang (cited in Berry et al., 2002a) highlights that psychology has more frequently than not tended to focus on the "individual as autonomous", and when compared to the African ideal, the person cohabits alongside the realm of spirits and with the natural environment (p. 106).

Between the 1960s and 1970s, the African culture began to grow its identity separate from the assumed ideas, enabling their community to develop more inherently (Berry et al., 2002a). Before that, research of Western, Eurocentric, or high-income countries had its power over the various other cultures all over the world, specifically African cultures (Guler et al., 2017). Their interventions, strategies, and understanding of ASD were seen in the light of their own research and were used inaptly as a form of treatment in cultures and communities different to theirs.

2.4.1 'I' becomes 'us'

To fully understand the Xhosa-speaking community and their way of living, it is crucial that the African personality theory is analysed, as it sheds light on the basis of their beliefs. Berry et al. (2002a) believe awareness of this theory will lead to diagnosis that is more efficient, effective relationships with and in families and the community, putting forward relatable treatments and an acceptance of treatment that can be applied to ASD. Previously, owing to the overarching beliefs and studies in the Western domain, Berry (2002a) notes that African beliefs did not seem to be and did not have a space to be portrayed accurately. The following section aims to describe a holistic, objective, and impressionable portrayal of African beliefs, as the participants of the study were from the Xhosa-speaking community.

The African ecological perspective and the African model of personality will form the focus of this section. Sow's (cited in Viljoen, 2003) theory of the "three cosmic orders or realities", namely, the *micro-cosmos, the meso-cosmos* and the *macro-cosmos*, can be integrated with the African model (p. 532). He assists us in understanding the African worldview, in that the person is not seen separately from the other contexts and spiritual realms, but that it all functions as one in a cosmos – "a harmonious system of realities" (Tabane, cited in Swart & Pettipher, 2016, p. 11; Viljoen, 2003).

This is similar to Bronfenbrenner's view that "the relationships between the organisms and their environment are seen holistically" (Donald et al., 2016, p. 40). This is important to consider for the study, as it forms the basis of the potential worldview of the participants and facilitates the process of understanding how each parent functions in his or her cosmos, contexts, and interactions.

Based on Moletsane's (2011) African model of personality, personality is comprised of and structured with levels: the body, the physiological and psychological, and the spiritual (see Figure 2.1) (as cited in Botha & Moletsane, 2012). The body is the shell of the person and aims to be constantly active. The physiological and psychological levels are both necessary for the body to be healthy, to have a stable mind and to survive. Sow (cited in Viljoen, 2003)

describes the interactions that persons experience every day in their community or "collective existence" known as the *micro-cosmos* (p. 535). These experiences are also influenced by the spiritual level.

The core of a person is the spiritual domain, but it also exists on its own, known as the *macro-cosmos* (Viljoen, 2003). Sow (cited in Viljoen 2003) describes this as consisting of "the domain in which God is encountered" (p. 532). In this *macro-cosmos*, Africans rely heavily on the belief that they are surrounded by a powerful being or supreme power who surpasses all of them (us) (Botha & Moletsane, 2012). The spiritual level which Botha and Moletsane (2012) describe can be seen as the "seed and inner part" and does not disappear even after the body has died (p. 71).

Still on the spiritual level, Sow (cited in Viljoen, 2003) continues explaining the extension of the level, the *meso-cosmos*, stating, "God has withdrawn and does not concern himself directly with the affairs of men; on earth, men (and woman) alone are responsible both for the good and the evil that may befall them" (p. 533). To elaborate, this is where chance and the spiritual forces of the ancestors, evil spirits, and sorcerers take control (Viljoen, 2003). The ancestors' role is to communicate and intercede between God and the people, as well as to take care of and protect their relatives. They can be described as people in the community who have passed away, but whose spirits are alive and existent among the living (Botha & Moletsane, 2012). According to Botha and Moletsane (2012), the ancestors "use dreams, signs, or traditional or spiritual healers to deliver the messages from God" (p. 70). Many Africans tend to relate conflict, illness, and death to the *meso-cosmos,* which influences their behaviour and way of thinking.

These separate but whole entities – "supreme power, the ancestors, a person, the environment, the family, and community" – need to find an equilibrium and aim to be peacefully connected (Botha & Moletsane, 2012, p. 71). This means that the different levels are in harmony with one another held together firmly and that the person can be happy and healthy (Botha & Moletsane, 2012, p. 71). In contrast, when persons are in a state of disequilibrium,

they are unhappy and vulnerable to illness, when the levels are not connecting, or they are weak and not working together as one. Accordingly, Viljoen (2003) refers to this as a "state of wholeness and integration" and then "a state of fragmentation and disintegration" (p. 542). Similarly, in the bioecological model, balance plays an important role in ensuring a healthy lifestyle. Donald et al. (2016) state that "when the relationships and cycles within the whole system are in balance, the system can be sustained", but if "there is a major disturbance in one part of the system … the balance of the whole system may be threatened" (p. 41).

The descriptions of the African personality model and Sow's three cosmic levels discussed above assist in understanding how the beliefs of the community are bonded with the aetiology and treatment of disorders and illnesses. Therefore, to diagnose and support a disorder like ASD, the levels of connections that could have been disturbed are important to consider (Botha & Moletsane, 2012). Practically, this would mean to look specifically for the challenges being experienced, understand them, and involve the family and collective community as part of the course of support (Viljoen, 2003).

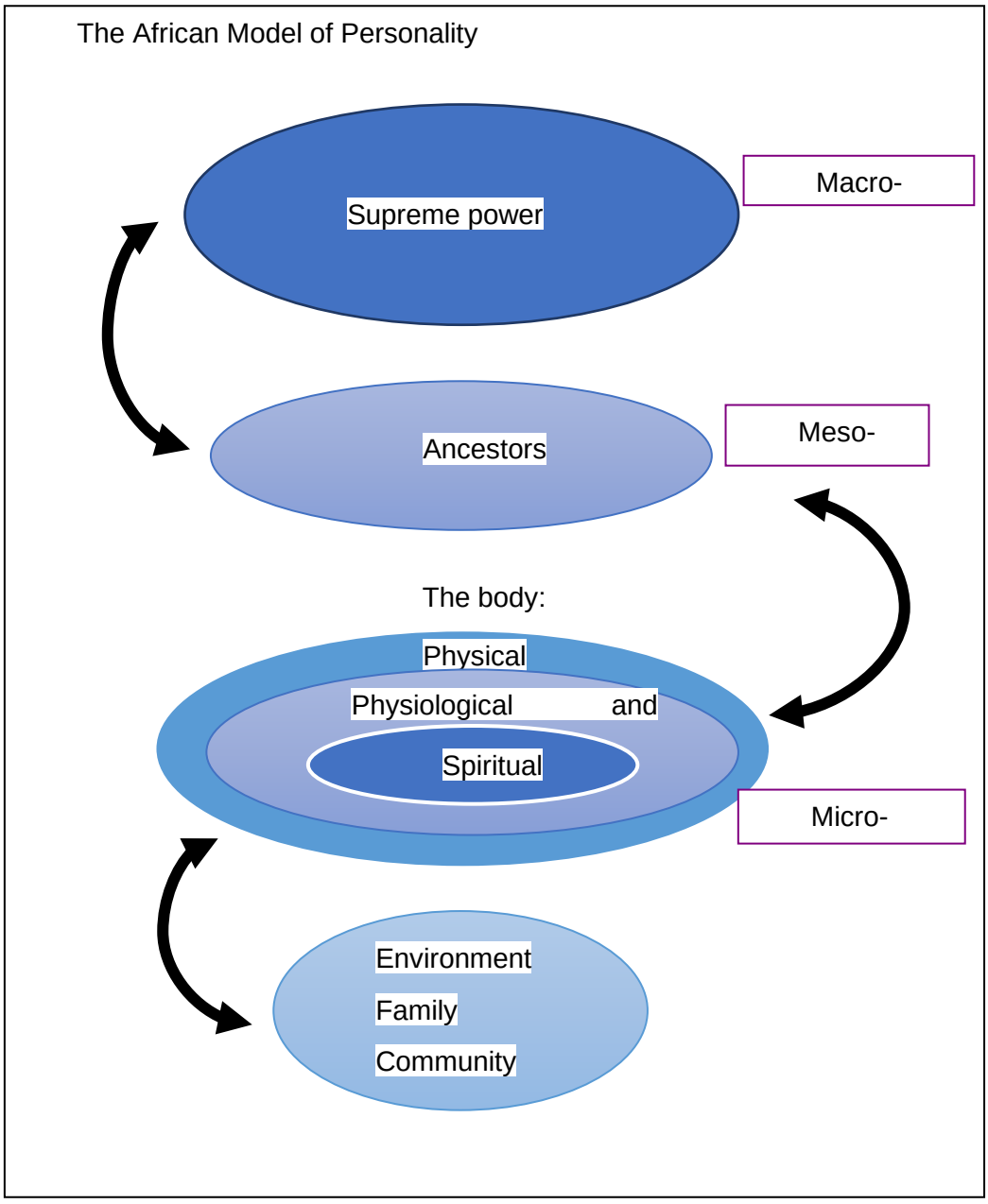
If we were to integrate the African philosophy with a model or theory taken mainly from the Western approach, we can use Bronfenbrenner's ecosystemic approach. It consists of various levels that are in constant interaction with one another and function as separate systems, too. It sees the person existing due to and within a set of systems and contexts aligning with basic premises in the African philosophy. In analysing the study, the integration of both ideas would assist in understanding the parents and their ideas better. Even though the African personality model gives perspective on understanding the meaning-making and realities of the African people; it is limited in that it does not elaborate on the influences of the various contexts in the *micro-cosmos.* The bioecological model provides in-depth understanding of the all-encompassing interactions within and between the cosmoses and contexts.

Finally, the gap that exists in research concerns the experiences of Xhosa-speaking parents and their understanding of ASD. To begin this process, with the goal of support in

mind, it was important to understand the Xhosa culture and their ways of living. In the South African Community Survey of 2016, it was found that about 80% of the population consisted of black African people (Stats SA, 2016). In the same survey, it was found that 31,1% (1 915 631) of people spoke Xhosa in the Western Cape (the focus of the study). Even though the South African population in the Western Cape consisted mostly of black African people, there was limited research on the Xhosa-speaking communities.

Figure 2.1

Moletsane's African Model of Personality and Sow's (1980) Three Cosmic Realities



Sources: Botha and Moletsane, 2012, p. 70; Sow (cited in Botha & Moletsane, 2012, p. 70)

2.4.2 Xhosa-speaking community

Mtuze (2004) makes a particularly important statement when he says that all cultures are fluid and therefore there cannot be “a homogeneous Xhosa culture” (p. v). However, for the purpose of this study, some parts of the Xhosa culture, also originally named the “Red Blanket People” are briefly and generally summarised for the reader, in order to shed light on the research topic (*The Xhosa - South African Culture*, 2021).

The Xhosa-speaking community forms part of the African family and their perspectives or ways of living. The Xhosa group mostly inhabited the land in the Eastern and Western Cape in 1593, with their spoken language (Xhosa) being an indigenous South African language (*The Xhosa - South African Culture*, 2021; Mzimkulu & Simbayi, 2006). According to research, some of their core principles or beliefs are that the Xhosa-speaking culture rely heavily on their ancestors for help and guidance and rely on the existence of community in all their daily endeavours and thoughts (Mtuze, 2004). The ancestors are responsible for looking after their people, the crops and cattle, and communicating through dreams or witchdoctors (*The Xhosa - South African Culture*, 2021).

When children are born, they need to be introduced to the ancestors, and the whole community celebrates the birth of a new child (Mtuze, 2004). Every person in the community needs to keep in contact with the ancestors for as long as he or she lives (Mtuze, 2004). “When illness occurs within the community, they regard this to be the doing of the ‘evil-minded’” (Mtuze, 2004, p. 69). Although some of the Xhosa culture seem to believe that humanity is born healthy, they believe that mostly “evil forces can cause bodily affliction” (Mtuze, 2004, p. 69).

The relationship between members of the Xhosa-community is deep and serious, as they place importance on a sense of community (Mtuze, 2004). The following statement by Mtuze

(2004) best describes this deep relationship: “If any mishap has befallen anyone of the blood relations[1] (members of the community), it is as good as having befallen me. My presence and help are required as though the mishap has happened in my household” (p. 90). This ties in with the African concept of ‘ubuntu’, which means wholeness. In other words, a person’s identity is made whole and enhanced by another person’s identity (Mtuze, 2004).

Ubuntu encourages human activities that persevere towards building up the community. Ubuntu believes in sharing, working together and being intertwined with one another, so much so that they become one, and finally, it is a way of life (Mtuze, 2004). This guiding principle is the basis of the Xhosa-speaking peoples’ beliefs and way of living. The study aimed to focus on the Xhosa-speaking community and how they responded to the phenomena of ASD. The goal was to provide a voice that would perpetuate a better understanding of the community within their community and within the Western society that would work towards integration of our varying or similar perspectives.

2.5 Previous Supporting Studies

In a few recent studies, there seems to be prominent commonalities in the challenges various parents, families, and communities have faced. The themes seem to be focused on misunderstanding or limited knowledge about the disorder. This led to discrimination, stigmatisation, and a lack of support from the community, which could instigate a delayed diagnosis. These themes could give an indication of the possible struggles the parents might face in the Xhosa-speaking community.

Stone-Macdonald and Cousik (2017) reviewed literature that was based on family perspectives and ASD from low- and middle-income countries and thus established similarities of families all over the world. The following similarities were found: Firstly, as there are many limited resources, a lack of knowledge and management of the disorder, as well as the trying process of finding and accessing supportive services, have created emotional and financial

[1] Blood relations: In the Xhosa culture, “fathers” refer to adult males, as well as “cousins” are brothers and sisters (Mtuze, 2004).

strain for families, especially parents (Stone-Macdonald & Cousik, 2017). Secondly, the idea of stigmatisation and discrimination of children with ASD is apparent in various countries and communities because others do not understand the manifestation of ASD (Stone-Macdonald & Cousik, 2017). Thirdly, although many parents benefitted from visiting support groups and receiving professional support, it was difficult for them to locate these types of support, and to keep consistently involved because of a lack of finances and limited time (Stone-Macdonald & Cousik, 2017).

Two studies completed in 2017 expressed similar results. Both studies used Kwazulu-Natal in South Africa as their target population and focused on parents who had children with ASD. Their aim was to explore an understanding of the culture, specifically, the African approach, as well as the presence and influence of the caregivers on their children with ASD and their potential future (Chambers et al., 2017; Mthombeni & Nwoye, 2018). It was found that there was a lack of knowledge and awareness, which led to difficulty recognising the signs of autism.

There was frustration with the improper support provided by both the health care system as well as the traditional healers, which led to many expenses that could not be afforded (Chambers et al., 2017; Mthombeni & Nwoye, 2018). It was also observed that the role of stigma and existence led to late diagnosis and support: The parents “predominantly believed that their children’s ASD symptoms were a punishment from the ancestors” (Mthombeni & Nwoye, 2018, p. 105); therefore “this community (also) experiences significant challenges of social stigma associated with having a child with a disability” (Chambers et al., 2017, p. 518).

In Guler et al.’s (2017) study, they explored the understanding of South African parents of children with ASD and the contextual factors that were important to consider during the intervention of ASD. Eight contextual factors were identified, namely “culture, language, location of treatment, cost of treatment, type of service provider, support, parenting practices and stigma” (Guler et al., 2017, p.4). These factors play a role in providing support for ASD, which can jointly facilitate and cause barriers in the intervention process. I have chosen to

highlight a few of the contextual factors in relation to my study, so that detailed understanding can be obtained of the influence of the Xhosa-speaking culture and how it could affect the perspectives of parents who have children with ASD, as well as the community. I shall highlight culture, support, and stigma factors.

Although ASD symptoms are found in African cultural communities, ASD is not labelled or understood as a neurodevelopmental disorder, which contrasts with the perspective of the Western ideals (Mthombeni & Nwoye, 2018). For example, some traditional beliefs and practices regard the spiritual realm as affecting one's well-being, and a person with ASD could be seen as being "cursed" (Guler et al., 2017). In order to care for a family where ASD is prevalent, it is important to consider how that family express their culture and to then incorporate it into the intervention (Guler et al., 2017).

Secondly, Guler et al.'s (2017) study mentions the risk or protective factors of 'support' in the context of the community (exosystem) and wider context (macrosystem). 'Support' refers to sources of support, like partners, grandparents, other parents in the ASD community, extended family, ASD professionals, schools and services, and the community (Guler et al., 2017). In the study, it was found that some of the challenges that can exist in the support systems are atypical family structures, single-parent households, co-parenting from different households, little awareness of ASD, and inconsistent patterns of support (Guler et al., 2017). Regarding parenting practices, Guler et al. (2017) report that parents had to change their traditional ways of parenting, specifically for their child with ASD. Many parents lacked knowledge about the correct way to discipline or understand their children's behaviour, experiencing a 'trial and error' process and certain insecurities about their parenting methods. In turn, this can harm the child and his or her future outcome.

Lastly, but most importantly, the study mentions the concept of stigma**.** Goffman (1963), as cited in Kinnear et al. (2016) describes stigma as "an attribute that is deeply discrediting" to a person, and which creates the idea that the person is being reduced "from a whole and usual person to a tainted, discounted – 'they'" (p. 3). Assumptions and labels are placed upon

a person and the associated group, which leads to social isolation and rejection of the person. The spectators tend to feel emotions of disgust, irritation, or fear towards 'them' and cause the stigmatised to feel lonely, ashamed, different, and embarrassed (Kinnear et al., 2016). The contextual effect of this can stimulate a cycle of exclusion from community activities, an unsupportive environment, and less access to goods and services (Kinnear et al., 2016).

Connell (2016), a person that lived with deafness and experienced stigma, learnt that stigma is ignited, not only by words, but through actions. In a study completed in 2017, which sought a group of Xhosa-speaking persons' understandings relating to stigma of schizophrenic people in their community, it was found that their stigmatism was related to "stereotypes (negative connotations), prejudice (ignorance or misinformation), and discrimination" (Matshabane et al., 2020, p. 5). Members of the community regard people who live with schizophrenia as "dirty" and understand the person to "become darker" (Matshabane et al., 2020, p. 5). The study concludes that the actions taken by members of the community to entice even more signs of rejection was to distance themselves socially and exclude members from participation in community or social activities (Matshabane et al., 2020).

For children with ASD, stigma is a reality. Gray (2002) completed a Western-based study involving several parents who had children with ASD. He recognised that certain factors seemed to contribute to the growth of stereotypes and stigma. These were confusion about the 'typical normal' physical appearance of a child, along with the confrontation of a disability, and 'odd', disruptive, and socially inapt behaviour (ASD). It did not make sense to them. Another factor that seemed to perpetuate the stigma cycle was the delayed process of diagnosis or lack of diagnosis that went hand in hand with a limited understanding of the manifestation of the disorder and what it meant (Gray, 2002). Many parents are made to feel they are to blame for the way in which their child acts and may be labelled by the community as 'naughty' (Guler et al., 2017).

The UNICEF (United Nations Children's Emergency Fund) is a program that supports and provides for the needs of children all over the world. In their global annually revised report of

2018, it was said that many children with disabilities (person characteristics) experienced barriers in their social and cultural contexts, which led to limited opportunities and a restraint on their potential (United Nations Children's Emergency Fund, 2019).

UNICEF continues to suggest that the beliefs from the macrosystem that are constantly perpetuated in microsystems like communities, neighbourhoods, and homes, can eventually cause even further damage between the mesosystems, creating negative and unhealthy processes. For example, children being restricted from going to school, the normalisation of abuse and neglect, as well as limited access to important services can create an unhealthy relationship and environment, disadvantaging the child (United Nations Children's Emergency Fund, 2019). The above-mentioned reasons reinforce the importance of this study, with the hope of introducing methods of altering people's attitudes, mindsets and practices of stigmatisation and marginalisation (United Nation Children's Emergency Fund, 2019).

Stigma is associated with many other disorders and shows its presence not only in the African communities, but also, as seen in Gray's (2002) study, in Western communities. Even so, the severity of the stigma in the African communities lacerates deeper due to African beliefs and traditions, which is also attributed to the denser lack of awareness of ASD and its manifestations. It seems to prevent parents from seeking support or a diagnosis. This then seems to push the parents into living in isolation from the community or even rejecting their child. Therefore, this poses a problem for the well-being of the family and the child with ASD. In effect, the cycle of stigma, discrimination, stereotypes, and an unhealthy community endures. Indirectly, the community tend to defy their core purpose of their culture to live in unity as one (collective existence) and contribute to their community.

In exploring the perspectives and experiences of Xhosa-speaking parents caring for children with ASD, the African philosophy needs to be understood first.

In finalisation, Hall and Hill (cited in Ravindran & Myers, 2012, p. 312) comment on the outmoded word 'disability' and the severity it carries – 'handicapped'. The perspective people have on 'disability' or 'handicapped' depends not only on the person (person characteristics),

but also on the beliefs and attitudes of the family members (process), their resources (from physical to emotional), the child and the family's ability to adapt to the environment, as well as the environment that adapts with them (context). It includes an unavoidable dependency on the legislation that supports disability (macrosystem, context), and lastly, the acceptance or rejection of the disability/handicap by the community (Ravindran & Myers, 2012). Therefore, it can be said that the role of the influence of the context in which a child with ASD exists, and the interactions in that context, can contribute to the severity of the disability.

2.6 Conclusion

"It is folly to transplant the practices of one culture to another environment and expect that everything will be acceptable simply because it is acceptable in its original culture" (Mtuze, 2004, p. 2). This statement by Mtuze reflects the importance of not trying to adopt another culture, for example the Western culture; values, beliefs, and way of thinking, to provide support for a different (African) culture. The study aimed to address this problem by discovering the perspectives of the parents of children with ASD in the Xhosa-speaking culture/community, providing them with an opportunity to be heard and understood, and not changed. ASD has become more prevalent in South Africa. There seems to be little evidence of Xhosa-speaking parents' understanding of ASD and of the support the children are receiving. To find out if there was a need in this area, this needed to be researched further.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

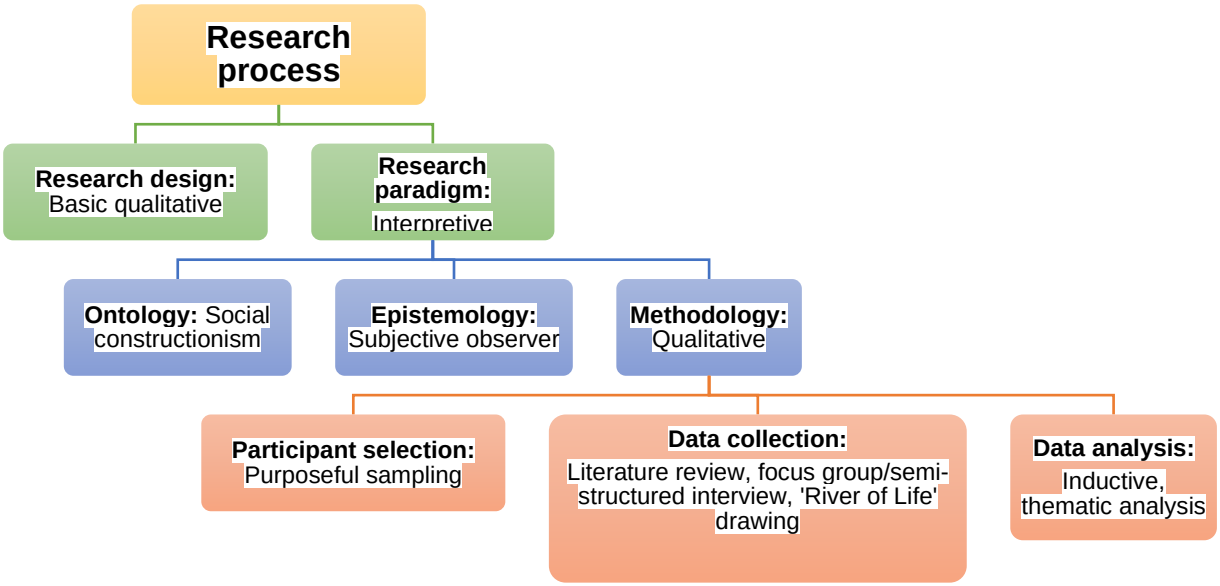
3.1 Introduction

As stated in Chapter 1, Section 1.5, the purpose of this study was to explore Xhosa-speaking parents' experiences of caring for their children with ASD. In addressing this purpose, the research paradigm and design that was utilised in more detail, the methodological decisions made, as well as the strategies that were used to ensure trustworthiness, are discussed in Chapter 3.

According to Agee (2009), researchers need to engage in reflective practice throughout the research process, using questioning, and should adapt their planning, if necessary, to delve deeper into understanding the perspectives of the potential participants. With the intention to gain detailed understanding of the perspectives of the participants in the study and their process of making meaning, the methods chosen had to be suitable and accessible (Flick, 2006). Below is a diagram of the research process that contributed to answering the research problem in its context.

Figure 3.1

Summary of the Research Process



3.2 Research questions

Some argue that the formulation of the research problem is often the beginning of many more questions that need answers (Agee, 2009). Dewey (cited in Merriam, 2009), though long ago, put forward a true definition of a 'problem' by stating that it can be something that "perplexes and challenges the mind so that it makes belief … uncertain" (p. 58). The research problem identified, namely the understanding of ASD in Xhosa-speaking communities, was a gap in knowledge among an omitted group of people.

Therefore, I explored the following primary research question: How do Xhosa-speaking parents experience caring for a child with autism spectrum disorder?

The study examined the following secondary questions:

v. What are Xhosa-speaking parents' perspectives of ASD?

vi. What is their daily experience of the diagnosis?

vii. How do the Xhosa-speaking parents experience the knowledge and misconceptions (if any) of ASD in the community?

viii. What is the Xhosa-speaking parents' experience of support and understanding in the community?

3.3 Research Paradigm and Design

According to Silverman (2013), a "paradigm provides an overall framework for how we [researchers] look at reality" (p. 111). Merriam (2010) elaborates on this notion by stating that reality is constructed socially and that it is difficult to discover only one observable reality, but that multiple realities can be interpreted. For example, various people witness the same event, but all of them experience it differently. The discoveries from this study were constructed by what the researcher heard and experienced from the participants sharing their understanding of ASD.

A paradigm can be placed within three dimensions: (i) ontology: the beliefs surrounding the nature of reality; (ii) epistemology: the beliefs surrounding the nature of knowledge; and

(iii) methodology, which determines ways to discover this reality in more practical terms (Merriam, 2016; Silverman, 2013; Terre Blanche & Durrheim, 1999). The researcher decides, according to her research goals, what reality and meaning needs to be studied (Terre Blanche & Durrheim, 1999). The reality that was listened to and interpreted in this study was the subjective experiences of parents caring for their children with ASD. This created an interaction that was intersubjective, which cannot exist without a relationship being formed "between the researcher and the participants" (Terre Blanche & Durrheim, 1999, p.6).

Intersubjectivity can be understood as:

> the interchange of thoughts and feelings, both conscious and unconscious, between two persons or "subjects," as facilitated by empathy. [Subjectivity is] the perception or experience of reality from within one's own perspective (both conscious and unconscious) and [intersubjectivity is] necessarily limited by the boundary or horizon of one's own worldview (Cooper-White, 2014, p. 1).

Although I needed to have my own boundaries in place with this approach, I aimed to create an environment of empathy and was cautious about becoming too involved in the participants' stories so that I was able to consider them critically but also with care (Rubin & Rubin, 1995). To clarify and explore the parents' experiences as effectively and empathetically as possible, a qualitative, basic interpretive approach was chosen.

The type of paradigm and design were chosen specifically to provide a platform for the parents to express their thoughts, stories, feelings, and their experiences- as experts of the study. As Kivunja and Kuyini (2017) eloquently state, the goal of an interpretive study is to attempt to "understand and interpret what the subject is thinking or the meaning they are making of the context" (p. 33). It guided me in emphasising the views of the parents, their subjective experiences of ASD, and controlling my own voice to understand ASD in the Xhosa-speaking community better (Kivunja & Kuyini, 2017).

Merriam and Tisdell (2016) argue that meaning also is created socially when individuals interact with and in their worlds, and therefore create their own understanding of reality. This

is known as social constructivism. This is when individuals' subjective meanings are developed according to the social, historical, political, and cultural factors with which they engage. The Xhosa-speaking parents' realities are constructed and influenced by the social systems with which they interact; consequently, meaning is made.

With this understanding of social constructivism, the concept of the African perspective could be embraced truly, as it related to the way they exist and function as a community – as one. Therefore, the interpretative-constructivist approach also indirectly gave the community an opportunity to share their stories and to speak in stories. This provided an opportunity for the Xhosa-speaking parents' perspectives to be shared, without the possibly overpowering Western ideals and concepts. The paradigm thus aided the process of presenting a pure account of the parents' experiences in their communities, the most important determinant for my choice of the research paradigm.

Creswell (2013) summarises the essence of the interpretive-constructivist paradigm that concurs with the intent of the study and highlights the second reason for my choice of the paradigm:

> In this worldview, individuals seek understanding of the *world in which they live* and work. They develop subjective meanings of their experiences … These meanings are varied and multiple, leading the researcher to look for the complexity of views … Often these *subjective meanings are negotiated socially and historically*. In other words, they are not simply imprinted on individuals but are formed through interactions with others (hence social constructivism) and *through historical and cultural norms* that operate in individuals' lives. (pp. 20-21)

The paradigm chosen also aligned with the theoretical framework for the study, namely Bronfenbrenner's (1979) bioecological theory, by showing that a person's ideas are created through the interaction of various, interrelated subsystems, emphasising the importance of the context in which the person lives. On a daily basis, people consistently interact socially in the community, the microsystem and macrosystem, which is influenced by the historical context

and cultural factors, known as the chronosystem and macrosystem in Bronfenbrenner's theory. These processes then form the peoples' reality.

In addition, interpretivism supports an inductive approach to data collection where the researcher uses observational skills, among others, to draw inferences or generalisations (Draper, 2004). Merriam's (2009) description supports the former writer and defines the inductive process as "researchers [who] gather data to build concepts, hypotheses, or theories rather than deductively testing hypotheses as in positivist research" (p. 15). To explore Xhosa-speaking parents' experiences of ASD, the data were collected by means of a literature review, semi-structured interviews, and an art activity, the 'River of Life' drawing.

With the mediation of the primary researcher, the participants were able to formulate their views through the multiple data-gathering tools and began the process of conceptualising and integrating new information with what was known in literature. The aim was to discover the raw details of the Xhosa-speaking parents' understanding and experiences that contributed to concepts that had been created from the Xhosa-culture and to distinguish this from the influence of the Western ideals. Thus, participants were allowed to create a new identity and a feeling of empowerment (Merriam, 2002).

3.4 Research Methodology

Merriam (1998) raises an important notion that gives purpose to the methodology of the research study:

> The realisation that knowledge-making is in itself a form of intervention has led to an increasing *emphasis on planning and executing research* in such a way as to make explicit provision for how the research is to fit into its real-world context. (p. 10)

Therefore, it was important that I carefully planned the methodology in consideration of the participants and their way of functioning, as well as to aim towards achieving a pure account of their experiences.

As the findings and interpretations of the study could be reviewed only within the parameters of the methodology, the next sections are devoted to discussing exactly how the research questions of this study were answered by outlining the group of qualitative methods chosen, which complemented each other. This included (i) the process of selecting the participants and details about the desirable participants that matched the goal of the study (ii); the selection of the research site; and (iii) how data would be collected, analysed, and interpreted. In this study, the qualitative methods chosen helped to understand the Xhosa-speaking parents' experiences caring for their children with ASD as suggested by Draper (2004).

3.4.1 Research participants

The participants were selected using purposeful sampling, a non-probability sampling method (Wolf et al., 2016). It was important to select the participants specifically, to understand and gain insight into the specific culture group being studied, with regard to the focus of the study: Xhosa-speaking parents who had children with ASD (Merriam, 2009). Patton (2002, p. 230) points to the value of purposeful sampling:

> The logic and power of purposeful sampling lie in selecting information-rich cases for study-in-depth. *Information-rich* cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry, thus the term purposeful sampling. Studying information-rich cases yields insights and in-depth understanding -rather than empirical generalizations. (p. 230)

A disadvantage of purposeful sampling, namely bias, should be acknowledged, although this was not intended. Selection bias can be understood as the process of recruiting participants by utilising the study inclusion criteria, and in doing so exclude certain people from the sample (Smith & Noble, 2014). Owing to limited access to the target population, the parents were recruited from one primary school where the parents were aware of their children's ASD diagnosis. None of the parents who met the inclusion criteria was excluded from the study.

Firstly, the parents were selected to be representatives of their children and their community, since they had first-hand experience of their children's functioning, and the reactions from and interactions with the community. Secondly, according to Predescu et al. (2018), parents are mediators for their children, facilitating the process of independent living in the bigger world, as well as facilitating the process of finding support. Thirdly, the children of the parents could not be considered. Based on the DSM-V and other research, the children struggle with communication and therefore would not be able to express their thoughts and feelings accordingly (American Psychiatric Association, 2013; Wing, 2002).

The following criteria were considered for including participants:

- Parents (biological mother, biological father, stepmother and stepfather, guardian, grandparent, aunt or uncle, or older brother or sister) who take care of a child with ASD.
- Having grown up in a Xhosa family, community, and/or culture.
- Selection from a government special school that catered for children with ASD in the parents' community in Cape Town.
- Caring for a child with ASD between the ages of 3 and 18.
- Caring for a child who had been diagnosed formally with ASD.
- Having given permission to include an interpreter/assistant during the focus group discussions.
- Parents who could understand and speak at least some English, as the researcher was not able to converse in Xhosa and needed the support of the interpreter.

The inclusion criteria for participants played an important role, as they directly influenced the goal of the study. Participation was voluntary; therefore, the sample size could not be predetermined. The selection from the target population consisted of three Xhosa-speaking parents.

3.4.2 Research site

Initially, I approached a school situated in a large Xhosa-speaking community in Cape Town for access to the target population. The school catered for children with ASD, and most, if not all, learners were from the Xhosa culture. It was important to me to select a school functioning in the Xhosa-culture only, as it would present an emphasis on the community as a whole and would show the extent of the influence of an 'untainted' community on the parents' experience of ASD, especially because they were in close proximity to one another. However, owing to circumstances during the COVID-19 pandemic, the school did not agree to participate in the study.

The second school I approached to recruit participants was situated in a neighbourhood in Cape Town that was more diversified with other cultures, of which many were Xhosa-speaking people. The school was selected because it catered for children with ASD. The school provided services for children between the ages of 5 and 13 years. Similar to the neighbourhood, the school consisted of a diverse set of learners, some coming from Xhosa-speaking families. Before acceptance into the special school, the children, along with the parents, went through the screening, identification, assessment, and support (SIAS) processes of the local Department of Education and thereafter acquired a formal diagnosis of ASD (Department of Basic Education – DOE, 2014). As a result of the children's' acceptance into the school catering for ASD, it was expected that the parents had some awareness of their children's diagnosis.

To enable the participants to access the venue easily and feel comfortable knowing where it was, the research site was situated at the government special school. With permission from the principal, a school classroom was used for the art activity and semi-structured interviews. A transport fare of R40.00 was provided for each participant to access the research site on the day of data collection without having to spend their own money. It was indicated that no other financial support would be offered. Participation stayed voluntary.

3.4.3 Selection process

The principal assisted me in identifying the Xhosa-speaking parents who had children with ASD in the school. An invitational letter (see Appendix C) was sent to these parents via their children's school bags or message books. The invitational letter included a section where the participants needed to confirm that they were Xhosa-speaking, had a child with ASD, and could understand at least some English. They completed this by reading the statements and ticking the appropriate boxes. This ensured that the selection criteria were met.

After the parents had responded to the invitational letters and confirmed their willingness to participate, the consent form (see Appendix D) was placed in the learners' schoolbags or message books. The participants were also able to request via the school, email, or SMS/WhatsApp that the consent form be sent to them electronically via WhatsApp or email.

The informed consent form provided the potential participants with the details of the study. This included the methods of data collection and the duration thereof, the benefits of being involved, as well as the risks, the possible representation of the data, and the understanding that they could withdraw from the study at any point in time without any consequences. The consent form also made the participants aware of the presence of an interpreter to facilitate communication. Where necessary, English was translated into Xhosa and vice versa, from Xhosa into English, during the interviews. The participants were able to rescind their consent to the interpreter's participation if they so wished, in which case the participant was not included in the research study.

Lastly, the participants were asked to sign, and in doing so, they acknowledged their voluntary participation, knowing the details of study.

3.5 Methods of Data Collection

3.5.1 Literature review

Theory is necessary in describing the phenomena of interest and supporting the research problem and questions. Silverman (2013) explains that "theory provides a footing for

considering the world, separate from, yet about, that world" (p. 110). Additionally, it assists in organising and understanding the incoming, active data. Therefore, the literature review can be understood as a compilation of key concepts, assumptions, beliefs, and theories that strengthen and inform one's own research (Maxwell, 2005). Essentially, it is based on revising previously researched and analysed data and fitting the data into conversation with one's research problem and questions.

During the first phase of the study, I utilised the Stellenbosch University library and made use of SUN Search, Google Scholar, EBSCOhost, Sabinet African Journals, Sage journals, and other databases covering the subject field to access literature. Some of the search terms that were used to search for data and literature were *African, non-Western, autism spectrum disorder, autism, stigma, Xhosa-speaking parents, parents, Bronfenbrenner, bio-ecological approach, culture, community,* and *beliefs.*

I sought to explore and familiarise myself with the African roots and how the culture perceived ASD. Initially, many articles were found based on the experiences of parents living with children with ASD all around the world. When I narrowed the search to the Xhosa culture and ASD, I identified a gap in the research. There seemed to be insufficient research with regard to ASD and the Xhosa community. The research studies that had been found were mainly from the Western perspective, which revealed the knowledge gap of the non-Western voice being heard.

To gain understanding of why this was the case, I started looking for articles that shed light on the traditions and ideas of the African culture. I discovered a juxtaposition in the way they functioned and understood ASD, compared to that of the Western ideals. Exposure to the ASD diagnosis seemed limited. This led to more interest in the reason behind this limitation. The search into gaining perspective on the African community showed that the context in which they functioned played an essential role in their understanding of ASD.

Bronfenbrenner's bioecological theory, the chosen theoretical framework for the study, seemed to be best suited to try and understand the surrounding influencing factors that could

play a role in their perceptions, in the Xhosa community context. As previously discussed in Chapter 2, although Bronfenbrenner's bioecological model is a Western theory, it focuses on the person existing due to and within a set of systems and contexts aligning with the basic premise of the researched African philosophy. It was important to move away from the Westernised influences and portray, from the beginning, the non-Western world and perceptions.

Finally, I believed that my research could fill the knowledge gap by involving parents of children with ASD in the Xhosa community in the Western Cape. The parents were more likely to have first-hand experience of ASD and would be able to voice their beliefs and ideas.

In this regard, the research purpose was to give the community an opportunity to share their ideas and ways of living. De Leeuw et al. (2020) clearly encapsulate that this would lead to "a better understanding of the cultural and contextual dimensions of ASD [and this] may also inform strategies to better support underserved communities in high-income countries", or otherwise stated, marginalised communities in a Western-dominated country (p. 6).

3.5.2 From a focus group discussion to individual semi-structured interviews

In planning this study, I aimed to incorporate fewer Western-focused ideas and to consider the African views and approaches that fit. After thoroughly studying the literature for the literature review, I realised how important community was to the Xhosa-speaking people. Therefore, initially, the planned focus group discussion as data-collection method seemed most appropriate for the study and the participants.

The importance of using a focus group was due to the collective way the Xhosa-speaking, African community function daily. Nsamenang (cited in Berry et al., 2002a) explains that the African culture perceives the functioning of the individual in terms of "a man is not a man on his own but is rooted in the community in which and for which he exists" (p. 107). The

structured focus group discussion hoped to facilitate a natural occurrence and way of relating, in order to encourage the freedom of expression of thoughts and feelings.

Stewart (2018) defines a focus group as “a type of group discussion about a topic under the guidance of a trained group moderator” (p.687). In addition, focus groups assist in providing a more casual approach that invites conversation and spontaneity, but also allows for a structured and organised process (Agar & MacDonald, 1995). By formulating the focus group schedule (see Appendix E), according to the aim of the study and in accordance with the research questions, I envisioned an environment that does not scare, but rather warmly invites the participants to share their thoughts and feelings (Krueger & Casey, 2009).

Although the planned focus group would have been the ideal data-collection method, the method had to be changed to individual semi-structured interviews due to varying circumstances. Focus groups also have disadvantages, amongst others, by taking the risk of limiting the researcher’s potential to delve deeper into each participants’ thoughts and history (Merriam & Tisdell, 2016). The semi-structured individual interviews provided a better alternative to overcome this disadvantage. Even though, at the beginning of the research process, interviews did not seem to be the best method for data collection with the Xhosa-speaking parents, there seemed to be coherence with the results of the study, specifically with regard to how the Xhosa-speaking parents seemed to have adapted in their community to function more individualistically. See Chapter 4 for more detail on this.

Other advantages included being able to facilitate the feeling that the participant was being heard and had an opportunity to have a say (Willig, 2013). As the researcher, I tried to understand what each participant was portraying, without impeding assumptions, allowing them to speak freely (Rubin & Rubin, 1995; Willig, 2013). It was of utmost importance that both the participant and I understood each other (Rubin & Rubin, 1995). The questions intended to be used in the focus group were applied to the individual semi-structured interviews. However, I cautiously and constantly contemplated the appropriateness of each

question, the direction of the conversation, and thereby mediated the structure of the discussion.

In doing this, I gained an objective but understanding perspective of the interview data. Silverman (2007) suggests that the data should not be revised as an “activity awaiting analysis and … a picture awaiting a commentary” (p. 56). The data rather should be perceived by our paradigm of interpreting and how the participants make meaning of their experiences, and then this should be portrayed as authentically as possible, with empathy and understanding.

With permission from the participants, the semi-structured individual interviews were audio recorded with a digital recorder and a recording app on my cell phone, for the sole purpose of making transcriptions later.

3.5.3 ‘River of life’ art activity

Along with the individual semi-structured interviews that took place, the participants completed an individual, creative drawing activity called the ‘River of Life’. The activity asked the participants to map their life journey, the ups and downs, by comparing it to a river: Wide parts of the river to narrow parts of the river, waterfalls to no water in riverbeds, rocks and trees were some of the symbols that were used to depict their experiences. They were then able to label the parts of the river with dates or words, where certain events, feelings and thoughts took place that had affected them and their lives.

The drawing activity had a dual purpose. Firstly, it was the second data-collection tool that was analysed and that contributed to the research and conclusions. Secondly, it was used to facilitate discussion of the participants’ experiences so that they had an opportunity to share their story through another medium. This was a visual artefact that supported the discussions explored.

3.6 Interpreter as Research Assistant

The interpreter, who also acted as a research assistant, helped with administration and writing notes on the day of the interviews and the activity. Firstly, she was responsible for

writing down the body language and gestures while the participants responded verbally. The aim of this was to contribute to a better interpretation of what the participants were trying to portray and communicate, especially since voice recordings were made which had to be transcribed. Secondly, being fluent in Xhosa and English, she translated verbal messages when necessary. With regard to admin, she assisted with preparing the venue and packed out the refreshments, helped the participants sign in, and handed out art material and other important papers.

She had undergone training in the professional field of languages and was in the process of completing her master's degree. She had training in human and research ethics. I had a meeting with her prior to the semi-structured interviews and art activity. She was made aware of the ethics of the study, her role and boundaries, and the process of the data collection. She signed a confidentiality agreement and was exposed only to the pseudonyms or first names of the participants.

The participants also had to give their permission for her to be present during their interview and art activity. This was communicated in the consent form. Before permission from participants was asked, they had been made aware of her role and duties, as well as the extent of her participation in the whole study.

3.7 Data Analysis

As the researcher, I took the responsibility of transcribing the recordings of the semi-structured individual interviews verbatim. I listened to them a few times to ensure accuracy of the transcription. During the transcription process, I was able to familiarise myself with each of the interviews and the art activities. The transcripts and the art activities were then analysed in depth, using thematic analysis. Fereday and Muir-Cochrane (2006) explain thematic analysis as "a search for themes that emerge as being important to the description of the phenomenon [under investigation]" and that grouping patterns together would lead to the finding of categories of meaning (p. 82).

Firstly, using the programme ATLAS.ti 9, I systematically labelled groups of meanings with codes. ATLAS.ti 9 is a programme designed to assist with analysing large bodies of qualitative data (What is ATLAS.ti, 2021). It provides tools to manage and arrange the data into codes and themes (What is ATLAS.ti, 2021). I read through the transcripts, the art descriptions, and viewed the art itself. While reading, I made comments and observations on ATLAS.ti 9. Sim and Waterfield (2019) suggest that the researcher analysis both what is being said, and how the person interacts and discusses ideas and thoughts. Therefore, it is important that the research not only considers the themes that emerge in conversation, but also include themes of the way they created meaning.

I then used *open coding*, where codes that were more descriptive or explanations were assigned to the data. It entailed labelling any information that I found that would contribute to answering the research questions. I used the system of coding found in the ATLAS.ti 9 programme and used phrases to code the important sections of data. In order to attach codes that were most comprehensive, the data were revised three times. *Analytical coding,* "coding that comes from interpretation and reflection on meaning" (Richards, cited in Merriam, 2009, p. 181), was utilised to create coding groups (Appendix H).

Secondly, patterns and connections of the codes were considered, to reflect themes related to the main research question (Willig, 2013). Merriam (2009) cites Day (1993) and explains it as:

The task to compare one unit of information with the next in looking for recurring regularities in the data. The process is one of breaking data down into bits of information and then assigning "these bits to categories or classes which bring these bits together again … then some may be subdivided and others subsumed under more abstract categories" (p. 177).

I then considered all the groups of coding and sought patterns in the data, connecting them and forming groups that could relate to potential themes. I revised the groups into subthemes, making some subthemes fall under a broader theme. After the first list of subthemes, I analysed them and changed or extracted or integrated them with other themes.

The transcripts and the descriptions of the drawings were read again, and I looked at the drawings to see if more data or examples could be found to fit into the more defined themes. I was in a constant process of refining and revising the data (Merriam, 2009).

Thirdly, the themes that were relevant to the study, relating to the research questions, were integrated into an interpretative discussion and analysis, with the goal of communicating and understanding the participants' experiences. The next part of the data analysis was to draw conclusions from the data, which formed part of the inductive process. Miles and Huberman (1994) describe it as transferring from the "empirical trenches to a more conceptual overview of the landscape. We're no longer just dealing with observables, but also with unobservables, and are connecting the two with successive layers of inferential glue" (p. 261).

A thematic map was used to sort the themes into concluding ideas and to integrate this into the final discussion and findings. Merriam (2009) suggests that "thinking about data-theorising- is a step toward developing a theory that explains some aspect of practice and allows a researcher to draw inferences about future activity" (p. 188). Next, I provided meaning, an understanding of the experiences of the Xhosa-speaking parents who have children with ASD, by conceptualising the data into themes within the bio-ecological approach.

3.8 Data-Verification Strategies

For the study and the body of knowledge to be trustworthy, I needed to ensure that the research was "rigorous, systematic and [that] the results can be trusted" (Merriam, 2002). Kvale (1996) emphasises how the constant examining of reliability and validity should take place throughout the entire research process. When elaborating on how to create validity in the research process, the authors Bright and Harrison (2013) encourage **"**establishing a rigorous relationship between the research aims, objectives, questions, and outcomes, together with a rationalised and transparently executed methodology" (p. 160).

I used strategies to achieve both reliability and validity in the study, labelled by Lincoln and Guba (cited in Kvale, 1996) as “trustworthiness, credibility, dependability [consistency] and confirmability [transferability]” (p. 231).

Credibility, also known as internal validity, attempts to portray the authenticity of the events experienced by participants and whether the interpretation is reflected accurately. Even so, Maxwell (2013) states that it can be difficult to fully portray the reality, in its purest form and continues to say that validity seems to be dependent upon prevalent factors: “It has to be assessed in relationship to the purposes and circumstances of the research, rather than being a context-independent property of methods or conclusions” (p. 121). This means there is an agreement that research participants’ reality is constructed socially and that they have their own interpretation of reality. Triangulation, member-checking, and reflexivity are some strategies that attempt to ensure internal validity or credibility.

The focus of this study was to discover the personal experiences and interpretations of the Xhosa-speaking parents that could not be replicated by another person/people. Thus, dependability (consistency), also known as reliability, aimed for the results of the study to be consistent with the data collected (Merriam & Tisdell, 2016). This means that the data accurately reflected the findings or conclusions. Member-checking was used to assist with this.

Although generalisability seems to be an important factor that contributes to validity, the study aimed to understand the experiences of the parents in depth, rather than apply a general truth about the parents across the population (Merriam & Tisdell, 2016). Thus, transferability or confirmability can be understood as “what we learn in a particular situation we can transfer or generalise to similar situations subsequently encountered” (Marriam & Tisdell, 2016, p. 255). It provides us with an understanding of what that experience could be like; in this case, what feelings or thoughts can be expected when caring for a child with ASD. To ensure transferability, rich, thick descriptions of the parents’ experiences were utilised.

In conclusion, I as the researcher favour what Wolcott (cited in Merriam & Tisdell, 2016.) says, “Every case is, in certain aspects, like all other cases, like some other cases, and like no other case” (p. 167). This was important to consider when attempting to gain an objective perspective and understand the uniqueness of every person. Validity, reliability, and the strategies applied aimed to promote the trustworthiness of the study.

3.8.1 Triangulation

Silverman (2013) interprets triangulation as “the attempt to get a ‘true’ fix on a situation by combining different ways of looking at it” (p. 287). The researcher used multiple data-collection methods, including semi-structured interviews, the ‘River of Life’ art activity with verbal storytelling, the assistant’s research notes, and my reflective notes. Theoretical triangulation also took place when I analysed the possible arguments in the literature review in depth. In addressing this, McLeod (cited in Bright & Harrison, 2013) states that “the aim of triangulation is to find agreement about the core meanings or themes. The act of interpretation involves locating the meaning of an experience or event in the context of a larger set of meanings” (pp. 86-87).

3.8.2 Member checks

Lincoln and Guba’s (1985) suggested method of member-checking was utilised to validate the data and confirm the credibility of the data. Bright and Harrison (2013 suggested that “asking participants to comment on the accuracy of data transcription and analysis can therefore be a helpful way of augmenting the validity of the work” (p. 162). The participants were shown the interpretation or findings that were presented in the manuscript. This step in the research process allowed me to verify or make corrections to the data, which would increase the trustworthiness of the study, as well as to ensure that their voice was genuinely captured (Harper & Cole, 2012). The participants were then given an opportunity to ask questions about the analysed data and could challenge assumptions made by the researcher.

3.8.3 Rich, thick description

Although the study involved a small group of Xhosa-speaking parents, the generalisability was secured by presenting detailed descriptions in the findings. This meant I had to present deeply descriptive information so that readers would be able to decide for themselves if the experiences would suit other situations, and therefore could be applied (Merriam, 2002). Firestone (1993) supports this idea by stating that readers need to decide for themselves what they can apply to their own lives and what they cannot. The reader and I need to ask ourselves if this situation that was experienced by the parents is relevant and applicable to other Xhosa-speaking parents.

3.8.4 Researcher reflexivity

“In qualitative interviewing, the researcher is not neutral, distant, or emotionally uninvolved. He or she forms a relationship with the interviewee, and that relationship is likely to be involving. The researchers’ empathy, sensitivity, humour, and sincerity are important tools for the research” (Rubin & Rubin, 1995, p.12).

As the primary researcher, I played a vital role during the research process. I was responsible for collecting and analysing data. Merriam (2009) states that the researcher, as the primary researcher, can perform tasks that contribute to clarifying and guiding the research process. These tasks involve the process of noticing indirect and direct behaviour that is communicated through the participants, as well as ensuring that the interpretations made are reliable (Merriam, 2009). Even though this is beneficial and an important attribute to the findings and conclusion, human instruments have shortcomings and biases that might affect the study (Silverman, 2013).

Lincoln and Guba (cited in Merriam, 2002) use the word *reflexivity* to describe the process as “reflecting critically on the self as researcher, the ‘human as instrument’” (p. 26). This provides the reader with a better understanding of how the information has been interpreted and analysed. It is important to note that I, as the researcher of this study, grew up exposed

to only Western ideals, literature, and beliefs. This could have influenced the interpretation of certain experiences related to the study, the process of data collection, interpretation of the findings, and the reliability of an accurate understanding of the non-Western culture.

As previously discussed in the literature review, culture encompasses a way of living, understanding, communicating, defining values and principles, and meaning making. This varies across many cultures and societies. The participants in this study were from the African culture and I, as the researcher, was from a Western culture. Both parties were aware of this, which may have created some distance between the researcher and the participants.

By being aware of one's own specialised vocabulary and cultural assumptions, one is less likely to impose one's own opinions on the interviewees. One wants to hear the interviewees ideas, and one does not want to block that communication by putting one's own assumptions in the way (Rubin & Rubin, 1995)

Before the data collection process, I ensured that I reflected on my assumptions about the Xhosa culture and my own culture and the explicit differences found. I continuously reflected on my own interpretations and the effects of my beliefs on the data collected, by writing in a reflective journal. I wrote down my thoughts and ideas before the study, while writing the literature review, during the data-collection process, and after data collection while analysing the data. I was able to ask questions, analyse the effects of my own beliefs and ideals on my interpretation objectively, and evaluate my own judgements critically. I engaged in conversation with my friends who were from a non-Western background and the Xhosa culture, enquiring about their ways, norms, ways of functioning; in order to gain some insight into the culture to relate better to the participants.

Moustakas (cited in Merriam, 2009) describes this process with a Greek word, '*ephoche'*: "The everyday understandings, judgements, and knowings are set aside, and the phenomena are revisited" (p. 25).

Although, the language of the participants was somewhat an issue, a Xhosa-speaking interpreter was present for the efficient communication of questions and responses throughout the interviews and art activity. The invitational letter and the consent form were also translated into Xhosa. The English versions ensured layman language, which was understood easily, and the participants were entitled to ask for guidance from the interpreter. It should be indicated that not all the Xhosa terminology can be related to the English language and concepts. This means that the essence of the meaning of certain concepts or phrases could be lost in translation.

3.9 Limitations of the Study

Even though the researcher had to adjust her data-collection method from focus groups to individual interviews, which seemed like a limitation, it did not necessarily affect the quality of the data. As previously stated, the researcher made many attempts to invite parents to participate in the study and made it easier for the parents to access the research site. Owing to rainy weather, difficulty with transport (the taxi may transport the participant only to the nearest landmark, making the participant walk the rest of the way), work over the weekends, COVID-19 anxiety, and precautions, as well as limited access to a limited known population (Xhosa-speaking parents with children with ASD); a limited number of participants were involved in the study. This influenced the method of data collection.

Even so, the opportunity to have in-depth individual interviews and conversations with the parents, gave the researcher a more personalised account of their experiences. In contrast to an individual interview, “in a focus group, participants are under pressure to perform and possibly to conform under the scrutiny of fellow participants” (Ransome, cited in Sim & Waterfield, 2019, p. 3011). Thus, it possibly made it more difficult for participants to share their views and ideas openly. The participants were risking themselves to be vulnerable, which could have evoked feelings of shame, embarrassment, and exposure. During the individual interviews, the researcher was able to avoid these possible feelings.

Differences in the respective cultures of the researcher and the participants may have caused some reluctance in participants to be open and comfortable with sharing their ideas in the environment. I hoped that the venue that they were accustomed to, and the presence of the Xhosa interpreter, would aid to the participants feeling more comfortable. In this case, I tried to be self-aware of my actions and thoughts throughout the semi-structured interview.

3.9.1 Sampling size

It is challenging to determine the sample size needed for a qualitative study with individual interviews. This seemed to be dependent on the purpose of the study and the methodology used. Adler and Adler (2012) indicate that qualitative studies usually have “fewer people, but delve more deeply into those individuals, settings, subcultures, and scenes, hoping to generate a subjective understanding of how and why people perceive, reflect, role-take, interpret, and interact” (p. 8). At the beginning of the research process, the number of participants was estimated. Even so, the sample size had to be revised during the research process at a later stage due to circumstances. It is important to consider the challenges posed that resulted in a few participants. This was dependent on the accessibility of participants and the resources (Flick, 2012). Malterud et al. (2016) indicate that an estimation of the sample size is important to consider and that the sample size be revisited during the research process, but that this cannot be predicted or controlled.

Although there were few participants in the study, the information provided was rich, descriptive, and adequate. Charmaz (2012) explains that even with a small sample, the study can be insightful and have significance, but that this is reliant on the developing research and the way the researcher manages the study and the analysis. To elaborate on this point, Malterud et al.’s (2016) *information power* model showed its support to this notion, which assisted in determining sample size. Malterud et al. (2016) explain that information power, meaning the depth/quality of information, is dependent upon the aim of the study, “sample specificity, established theory, quality of dialogue and the analysis of strategy” (p. 1757).

Therefore, the more *information power,* the smaller number of participants are needed (Malterud, 2016). With regard to analysis of the interview data, Psathas (1995) points out that it must be able to attempt to answer the research questions and be “uniquely adequate for that particular phenomenon” (p. 51). I ensured that the interview questions were able to facilitate and guide the participants to open up and reveal their deeper thoughts and feelings. Ogden and Cornwell (2010) proclaim that the interview questions can create richness and depth to the data; therefore, the questions need to be thoroughly revised and purposeful.

The aim of the study was to explore the experiences and accounts of the Xhosa-speaking parents and not describe all the components of the manifestations of ASD in the community. In addressing this, Malterud et al. (2016) states, “We *(as researchers)* are usually satisfied when a study offers new insights that contribute substantially to or challenge current understandings” (p. 1759). The study and its findings hoped to begin the process of challenging current thinking, making the readers aware of the difficulties being faced, and providing new insights. The study has shown that there is a need for further development and assistance in the Xhosa-speaking community with regard to ASD.

3.10 Ethical Considerations

Brinkmann and Kvale (2009) notice that during the research process, ethical dilemmas sometimes arise, and they encourage researchers to stay ethically aware and to adopt an ethical approach consistently in all their actions. According to Rubin and Rubin (1995), research ethics is fundamentally about researcher’s actions to obtain information in a trustworthy manner without causing harm to the participants involved in the study. Allan (2016) suggests four ethical principles to achieve this: (i) autonomy and respect for the dignity of people; (ii) non-maleficence; (iii) confidentiality and anonymity; (iv) beneficence. Each of these principles, as well as the process of ethical clearance, will be discussed next in relation to the study.

3.10.1 Ethical clearance

Before beginning with the study, I applied for ethical clearance to the Research Ethics Committee of Human Research (Humanities) (REC) of Stellenbosch University, which was granted (Appendix B). I applied for ethical clearance to add to the validity and reliability of the study, and so that the outcomes of the study could make an important contribution to the ASD community.

Part of the application was to first obtain permission from the school to gain access to the research site (Appendix F) to invite Xhosa-speaking parents of children living with ASD, to participate in the study. I did not have access to the contact details of potential participants, (that is, the parents), to abide by the POPIA Act that was promulgated recently (Protection of Personal Information Act – POPI Act, 2021). The parents were contacted and invited to participate in the study by sending an invitational letter (Appendix C) via the children's school bags or message books. Seeing that the school is a public school in Cape Town, the Western Cape Education Department (WCED) also gave permission to conduct the study (see Appendix I).

After the invitation letters had been sent to potential participants, only one participant accepted. The other participants declined because of financial constraints. After discussing the problem with my supervisor, I decided to make amendments to the study and include financial compensation of forty rand for transport fees for each participant to be able to participate in the study. I also combined the art activity and the focus group to take place on one day, instead of two days as was planned initially. These changes were reviewed by two reviewers of the Departmental Ethics Screening Committee (DESC) of the Department Educational Psychology, and accepted by the REC. The study then proceeded, and written informed consent letters were sent to potential participants via the children's school bags or message books (Appendix D).

3.10.2 Autonomy and respect for the dignity of people

The basis of informed consent included a detailed explanation of the study, what the participants could expect to encounter during the research process, as well as the risks and benefits involved. The participants were informed about these terms in the written informed consent letter, which was not only in English, but also translated into Xhosa. I needed to ensure that the information shared was accurate and that the participants could understand what was being explained. The participants were not forced or manipulated into participating, and they were made aware that it was entirely voluntary (Sim & Waterfield, 2019). In this way, I was able to consider the needs, and autonomy of the participants.

The transport fee as financial compensation was calculated carefully and researched to ensure that the remuneration remained a recruitment incentive and did not become a benefit of study participation.

The participants were also reminded that they might withdraw from the study at any point without any discrimination from myself and/or the interpreter. In the event that a participant wished to withdraw, I planned to ask the participant if any information that had already been shared by the participant might be included in the manuscript. Consent was confirmed again by the participant when they were given an opportunity to read through the interpretation of the interviews in the manuscript and confirm that the interpretation was accurate. If the participants disagreed to the information being shared from their interviews, their contribution would be removed and not be included for thematic analysis.

The participants autonomy and right to be respected was furthered considered in that they were informed of the risk in consenting to participate in a focus group. Firstly, they were agreeing to being vulnerable with their lives, and secondly exhibited this in a group of possible strangers or friends (Sim & Waterfield, 2019). This then also links to the ethical principle of non-maleficence, not to cause harm to participants.

3.10.3 Non-maleficence

I was not able to promise protection from discrimination against participants by the other participants during the planned focus group. “The nature of the group setting is such that participants are obliged to express in public what they usually regard as private, and neither the reaction nor the discretion of the group can necessarily be predicted” (Sim & Wakefield, 2019; Wellings et al., 2000, p. 256). Furthermore, participants were made aware that full disclosure to others who did not belong to the group could be compromised. Therefore, in the consent form, group members were asked not to disclose any information shared in the group. It was the responsibility of the group to commit to this agreement.

The researcher planned to prevent this from occurring by discussing ground rules at the beginning of the focus group (briefing), and by showing through example, respect and acceptance for all the group members, as well as debriefing at the end of the planned focus group sessions. Additionally, I planned to remind the participants of the agreement at the beginning and end of the focus group discussion. As the focus group could not be utilised as a data-collection method, as discussed in the limitations of this study, the ethical risks associated were mitigated.

If a participant wanted to leave the interview, the researcher was able to debrief the participant immediately afterward, and the person was provided with the researcher’s contact details. While participants shared information about their lives, views, and feelings, which could be the first time for some of the participants, other feelings that had been kept safe in their minds and hearts could emerge, evoking possible anger and/or sadness and/or disappointment. This was identified as potentially harmful to the participant if it were not handled efficiently. I stated in the consent form that it might be possible that feelings might arise that would be uncomfortable, and that the participants might want to contact the free counselling service recommended, to mitigate this risk. If feelings arose during the semi-structured interview, I contained the situation and reminded the participant of the support service.

3.10.4 Covid-19 precautions

Owing to the COVID-19 pandemic that has been present and continues to be for people all over the world; specific and careful precautions were put in place to protect myself and the participants from harm. The venue and any other materials or tools used in the process of data collection, was sanitised before the participants arrived and thereafter. When participants arrived, they were asked to complete a health screening form eliciting information on their health status and their social interactions, that is specifically linked to symptoms and risk of infection of the coronavirus. Participants had to sanitise their hands before entering the venue and after leaving the venue, this also included taking their temperature and recording it.

Only participants that showed no risk of infection or infecting others with the virus were allowed to enter the venue. The participants, the researcher and assistant were placed two meters from one another during the interview and were always required to wear a mask. As a further precautionary measure to safeguard the participants, the researcher, and the public; the contact details of the participants were written down. This was put in place in case the participants needed to be contacted and informed of a confirmed positive test result in order to self-isolate. The contact details of the participants were not used for the study and was destroyed in a month of the interview session.

3.10.5 Confidentiality and anonymity

Sim and Wakefield (2019) explain that confidentiality and anonymity are two different aspects that need to be addressed separately but need to be connected. They continue to suggest:

Confidentiality relates to what is done with the information once it is in the researcher's possession, and specifically the extent to which it is disclosed to others. Anonymity, in contrast, is concerned with the attribution of information- can individuals be identified from the data that they provide or from other information relating to them? (p.308)

The private venue at the school provided a safe place for the participants to express themselves freely. Any information and responses received from the interviews and the art activity were kept confidential and anonymous by assigning pseudonyms. The school and school community were kept anonymous as well. The only time the information would be shared, would be in the rare event that it be required by law.

I did not access the learners' case files, and the biographical information requested by me in the informed consent letter was read only by the researcher. This was stored in a private file and in a securely locked cupboard.

The audio recordings and transcriptions in preparation for data analysis were stored on my computer and shared with my supervisor, Ms Carla Feenstra. For protection and to mitigate risks such as loss of data or theft, it was also stored safely on the online platform, Google Drive. Both platforms were protected with a password that was known only to the researcher and her supervisor. The audio recordings were transcribed by a transcriber, who signed a confidentiality agreement, and it was sent already anonymously with pseudonyms. After analysis, the data set is stored on the online platform of the university, namely SUNScholar, for ten years, which is safe and secure and aligns with the newly promulgated POPIA Act.

The findings of this research would be reported and published in a thesis that would not contain any data that could identify the participants or the school. Any information that could identify participants would be erased from the researcher's computer, cell phone, and Google Drive once the thesis had been completed. All participants were made aware of the above-mentioned information verbally and as stated in the consent form.

3.10.6 Beneficence

The researcher took care to formulate the interview questions with benevolence and reflection in mind and ensured that the questions were facilitated by guided research examples.

Lastly, I hoped that the study would fuel a relationship between the participants and that they might feel empowered to begin their own support group, separate from the study. I hoped that the formation of the focus group would become a support group for the parents who had children with ASD in the Xhosa-speaking community. According to Drury et al. (cited in Harper & Cole, 2012), “research and therapy can sometimes be intertwined, meaning that during the research process, a participant may receive a therapeutic benefit” (p. 1). This could have been beneficial, by providing a safe space for the participants to share their feelings and be supported, normalised by the rest of the group (Sim & Wakefield, 2019).

This was stated clearly in the consent form and was explained to the participants on the day of the individual interviews, and particularly during the second session of interviews. I had to manage my expectations with regard to this by only suggesting a support group and not making it the aim of my study.

3.11 Conclusion

Chapter 3 gave me an opportunity to explain the paradigm, the research methods, and study design employed in more detail. All of these played an integral role in providing a trustworthy process and analysis of the study. The research question, namely how Xhosa-speaking parents’ experience caring for their children with ASD, was answered rigorously based on the research methods used. The process of data analysis was discussed in detail, for the sake of transparency, including the ethical considerations and data verification strategies that would need to be studied. Chapter 4 will present the data in detail, followed by Chapter 5 with a summary of the findings, recommendations for further research, and a discussion of the limitations and strengths of the study.

CHAPTER 4

RESEARCH FINDINGS AND DISCUSSION

4.1 Introduction

This chapter aims to outline the main themes that were found in the data set following rigorous thematic content analysis. The themes will be presented and supported by illustrative quotes, followed by a discussion of the specific theme, relating to the purpose of the study. The purpose of the study was to explore Xhosa-speaking parents' experiences of caring for a child with Autism Spectrum Disorder. The secondary questions that assisted in understanding the full extent of the parents' experiences and acted as a guide for the semi-structured interview questions were:

i. What are Xhosa-speaking parents' perspectives of ASD?
ii. What is their daily experience of the diagnosis?
iii. How do the Xhosa-speaking parents experience the knowledge and misconceptions (if any) of ASD in the community?
iv. What is the Xhosa-speaking parents' experience of support and understanding in the community?

4.2 Context of Research

To contextualise the findings, the participants and the context of the study were reviewed before the themes and subthemes were detailed. As described comprehensively in Chapter 3, Section 3.5.1.2, the initial intended goal was to form a focus group of three to five Xhosa-speaking parents and to have them discuss their experiences. However, the outcome was different and forced the researcher to engage in semi-structured individual interviews instead. The art activity, the 'River of life' drawing, still acted as a medium to mediate the discussions with the participants.

The participants were all Xhosa-speaking mothers between the ages of 33 and 36. They had all grown up in a Xhosa community and had one child with ASD. Every child had received

an official diagnosis, and the children's age ranged from 8 to 10 years old. The participants (the parents) were selected from the parent community of a special school that catered for children with ASD. Therefore, the parents were aware their child's diagnosis. The mothers travelled from various places in Cape Town, Western Cape, for the interviews. Table 4.1 below summarises the participants' family arrangements.

Table 4.1

Participant Information

Participants	Status in family	Age	Age of child with ASD
Participant 1: Fatima*	Mother – Single	36	9
Participant 2: Anne*	Mother – Separated	33	8
Participant 3: Cathy*	Mother – Married	34	10

* Pseudonyms

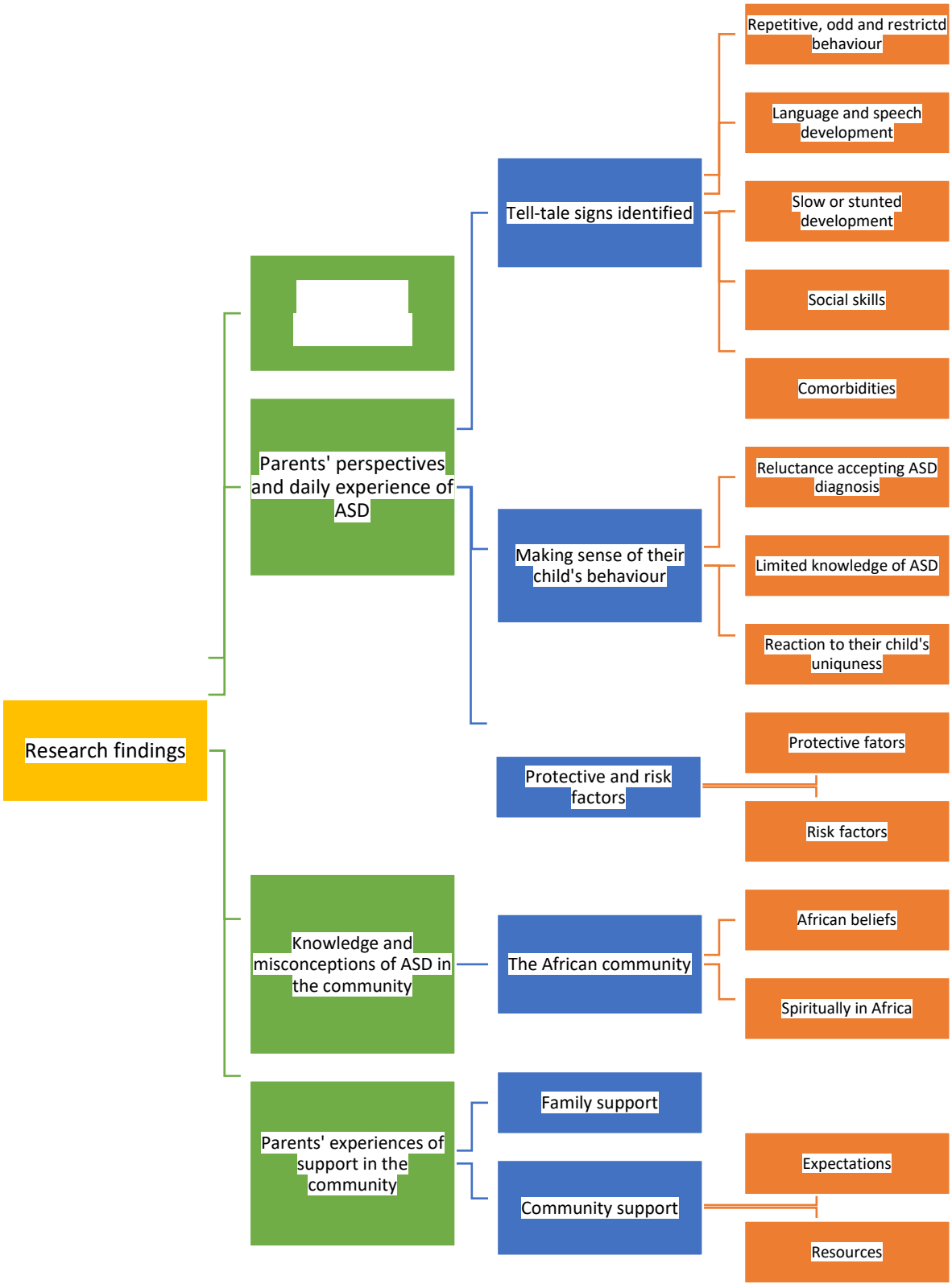
4.3 Themes, and Discussion of the Research Findings

The experiences of the parents' caring for their children with ASD in the Xhosa community elicited rich descriptions, which were categorised and further narrowed down to subthemes and themes. Six themes were identified, namely (i) the parents' tell-tale signs identified; (ii) making sense of their children's behaviour; (iii) protective and risk factors; (iv) the African community; (v) family support; and (vi) community support.

The themes and subthemes are discussed in an integrated manner, in that some of the secondary questions of the study are combined to answer the primary research question. More specifically, Xhosa-speaking parents' perspectives of ASD (Question 1.1) is presented in conjunction with their daily experience of the diagnosis (Question 1.2). This is followed by a discussion of the Xhosa-speaking parents' experiences of the knowledge and misconceptions of ASD in the community (Question 1.3), and lastly, the parents' experiences of support and understanding in the community (Question 1.4) are discussed. Figure 4.1 summarises the themes and subthemes in relation to the research questions.

Figure 4.1

Themes and Subthemes of Findings



4.3.1 Parents' perspectives and daily experience of ASD

It was important to delve into the parents' retelling of their daily experience with ASD. It provided a pure representation of how ASD manifested, how it was understood and how it influenced the parents and their respective families in the Xhosa community. Parents play a vital role in facilitating the process of diagnosis, with managing and supporting their children's growth and their overall development (Viljoen et al., 2019). Throughout the research process, the parents, all of whom were mothers, shared how they had received a diagnosis and discussed how they had been dealing with it since.

4.3.1.1 Theme 1: Tell-Tale Signs Identified.

Theme 1 considered how the mothers perceived the behaviours their children displayed daily. All the mothers seemed to have noticed that there was something different about their children and their development. Once the children had been exposed to more interpersonal relationships in society, the unusual behaviour seemed to become more explicit (Stone-Macdonald & Cousik, 2016). The mothers' initial awareness showed that they had a degree of understanding of important developmental milestones. Therefore, being aware of their children's uniqueness enabled the mothers to identify many of the tell-tale signs of ASD.

The theme is divided into five subthemes, namely (i) repetitive, odd, and restrictive behaviour; (ii) language or speech; (iii) slow or stunted development; (iv) socialising; and (v) comorbidities. The highlighted categories resonate with the diagnostic criteria in the DSM-V, impaired social interaction (which includes communication) and restricted behaviour (refer to Appendix A) (American Psychiatric Association, 2013; Wing et al., 2011).

i. Repetitive, odd, and restrictive behaviour.

The mothers spoke about their children displaying odd behaviour that also became repetitive and restricted. Wing (2002) relates this to a limited imagination and understanding of people, where children with ASD find enjoyment in repeating activities that they are able to do. Cathy spoke about her child laughing inappropriately:

Laughing while she's walking alone.

Fatima pointed to the restrictive behaviour when she shared the following:

They put, they make the things in line because that is what is happening in their mind. Other reports of repetitive behaviour that caused concern for the mothers were repetitive hand movements, jumping, and sensory issues:

Or just the facial expressions. And the hand gestures, sometimes she has that but not a lot. [Cathy]

He used to do all those things like jumping and close his ears. [Fatima]

Then there by the creche. They said yoh, your child is biting other kids when he is angry. [Fatima]

Why is Liso like licking now? [Fatima]

Before he eats something, he smells it – everything, he smells it. [Fatima]

In a thirty-year review of literature on stereotypic behaviour, the behaviour mentioned by the mothers were found commonly in other reports of children with ASD (Digennaro Reed et al., 2012). Examples are “licking, mouthing or smelling objects, hand or finger posturing, addition of objects to a line, non-contextual laughing/giggling, jumping and non-functional body tensing/posturing” (Digennaro Reed et al., 2012, p. 425). Each mother’s child displayed different behaviours, and it varied from mild to severe on the ASD continuum. Even so, this showed that the symptoms reflected ASD and could be connected to ASD, even though the children and parents were from another culture and upbringing. The behaviours remain familiar to the manifestation of ASD.

The mothers were not able to explain the rationale for the odd behaviour and consequently had trouble labelling it. An ASD diagnosis failed to show exactly what the symptoms would be and how it would manifest due to the wide range of stereotypic behaviour found on the continuum (Wing, 2002). Nevertheless, the mothers tried to understand their

children and not reject their behaviour. The mothers used their force characteristics by discouraging reactions from their social context that could possibly have the potential to disrupt the healthy processes of the mother-child relationship and then the acceptance of ASD in their lives (Bronfenbrenner & Morris, 2007).

ii. Language or speech

A prominent subtheme throughout data analysis was that the children's language or speech was affected. It was one of the more specific behaviours that caused concern among the mothers. Wing (2002) states that communication is very dependent on a person's ability and understanding of language, like using and understanding speech, intonation, and voice control, as well as using and understanding non-verbal communication. Thus, the child's language development is dependent on the resource characteristics of the child. This influences the interactions the child has with everyone in his or her microsystem: parents, friends, family, neighbours, et cetera.

Cathy's child struggled to speak at the appropriate age. She noticed that there was a delay in her daughter's speech and that she was not relying on her mother for her basic needs.

She started walking like children; instead, the main problem is her speech. She was just too independent. Like, she'll never ask for anything. She will just do it; if she knows where the toilet is, she will go and then help herself. If she wants water like there was no, you see what children are, they are talkative at that age, like, one or two, three. You can see that the things they do, they talk, but she was not. She just wanted to do things herself. [Cathy]

Fatima's child's speech seemed to have developed in a different language, other than his home language. After a while, he stopped speaking and sometimes would use only one-word phrases.

So, he was growing, growing, growing well and then at the age that he can start speaking, he speak. But he was speaking Afrikaans and my language (Xhosa) he used to

understand but he cannot speak, but he can speak Afrikaans. So as the time goes on, the speech, like stopped talking. [Fatima]

He's cutting the words like, he use to say 'mama' … small words, like he doesn't finish the sentence. Like if he wants something, he can just say 'bread' or 'water', not only say that 'mommy can you please get me water?' [Fatima]

Anne's daughter had a mild case of ASD. She spoke fluently, but chose to speak in English, which was different to their home language, isiXhosa.

Like when she was three, she was speaking English, and like it was not just the normal English, it was (laughs) – when you watch Mickey Mouse, it was that high grade English like whooo (made like it was 'fancy' English) – whatever, so she had that accent. [Anne]

Similar to Anne's daughter, Wing (2002) describes that in some cases, a child with ASD may have inappropriate intonation and volume, which sounds monotonous or robot-like, or may mimic sounds or other people. Along with this, Anne's daughter displayed poor communication skills, which affected the way she would understand language and social situations.

We went to the park; we saw this and that, but now I had to probe her when it comes to that. What happened? Did you go to the park? And then she will repeat what I'm saying – the park. What happened? Then she will give you a one-letter word answer and then I was like, okay, there is something wrong here. [Anne]

Her mind is of a 10-year-old, that's how intelligent she is. However, in terms of communication, so she was 5 turning 6, her communication level is for a 3-year-old. [Anne]

Even though the studies were completed in different years and contexts, both Volkamar and McPortland (2014) and Wing (2002) had commonalities in their observations of communication and speech. In Volkmar and McPortland's (2014) study, it was reported that most parents in South Africa experienced echolalia as a common sign (Mthombeni & Nwoye,

2018). Wing (2002) states that it is common for children with ASD to have either delayed or abnormal speech, such as echolalia, and to experience difficulties in conversational skills.

iii. Slow or stunted development

The mothers seemed to notice that their children's development deviated from the typical developmental phase milestones. This showed that they had knowledge of the different developmental phases and associated milestones children were meant to go through. Anne was able to compare her own child's development to her older neurotypical child, as well as her sister's child. She noticed that her child was developing at a slower rate.

The red flags are there, like I'm able to pick up, okay, this child is slow, so this is not happening, this was not what happened to the previous child I had. And then, in that, I was like, oh okay, the children are different. [Anne]

My sister has a child, I think they are three years apart. But then when she's at home, when you visit my mom, then I could see, no man, my sister's child is more advanced in everything that she does. [Anne]

Anne pointed out that her daughter's father seemed to notice that their child was slow in reaching her developmental milestones.

When she grew up, most of the things, he used to be the one that notices. Do you see this child? Yoh, this child … because Alice, when she was one, she could walk, she couldn't crawl, she was crawling with her tummy, but she didn't use her knees. So, he was the one who picked those things up. Do you notice that this child doesn't walk, doesn't do anything? And then when she started walking, around 1 year, 7 months – she was almost 2. She also started, she stood up and starting walking. [Anne]*

Fatima explained that her son did not go through all the usual developmental milestones, but that he skipped some of the important skills, like crawling.

So, instead of crawling, he just tells himself that, okay I'm not going to crawl, I'm just going to stand up. He just passed the steps that he is supposed to do. [Fatima]

iv. Socialising

All the children seemed to struggle with engaging in socially appropriate interaction. Cathy pointed out that her daughter did not like to connect with other people or children.

She doesn't get to meet other children. It's not something you can force. I really cannot force her to go outside and learn how to speak. She doesn't like it. She doesn't want it. She doesn't connect, there's no connection with other children. [Cathy]

Anne's daughter appeared to have a similar way of functioning.

So, she doesn't play – that doesn't bother me, she doesn't have friends. She's playing in the house, and with them. They love cartoons, so she can stay watching TV the whole day. [Anne]

In addition, even though Anne's daughter had been diagnosed on the spectrum with mild symptoms, she still struggled to know how to interact appropriately with others.

She doesn't talk to anyone if she is not introduced … then she ignores you – like you here, but then you're not here. [Anne]

Because she is straight-forward, because if she doesn't like something, she tells you in the face, listen what you are doing, I don't care – I don't like it. Like she doesn't care whether how old you are or whatever. If you're rude, she tells you straight, 'Granny, you are rude - I don't like what you are doing'. [Anne]

Both Cathy and Anne remarked about the fact that their children seemed to be in their own world, which seemed to make it difficult for the mothers to connect with them then.

But most of the times she keeps to herself. [Cathy]

She is fussy, because sometimes you can then tell, oh, she's in that world now, so we need to ignore her. [Anne]

What the mothers were alluding to with regard to the social interaction difficulties coincides with the phenomenon of 'theory of mind'. It can be described as a "lack of

understanding of other people's thoughts and feelings" (Wing, 2002, p. 21). They struggle to empathise and connect with others. This lack of interaction and connection tends to endorse judgement and stigmatisation from the community or the people in the microsystem, which in turn creates a type of isolation from the community.

v. Comorbidities

Even though the mothers did not label their children's relating behaviours to co-morbidities, the mothers noticed that their children struggled with either hyperactivity, impulsivity, or concentration. This aspect seemed to be identified only after the children's interaction with the school context and people in the community.

I noticed in terms of her concentration span she is a low, a low concentration span – like she cannot concentrate for so long. [Anne]

Fatima explained her son's difficulties, not only with impulsivity and hyperactivity, but also his limited awareness of other people's space and belongings. This can also be an attribute of s*ocially inappropriate behaviour.*

Because he's got a, a small hyperactivity, like, when he goes to next door, maybe just go, and open the TV and open the cupboards and all those things, and then I need to go and explain but no he is like this and that and that. [Fatima]

Other co-morbidities could be an intellectual disability, which Cathy seems to refer to as follows:

She develops slow than the normal children her age. So, she might be 10 but her brain is like a 6-year-old, 5-year-old. [Cathy]

Yeah, her brain especially. The other things – she might have breasts … but her brain is still like a child's. [Cathy]

ASD is currently represented on a continuum of severity, or on a spectrum with the possibility of comorbid conditions (Wing, 2002). As the behavioural traits of ASD were explored

among the children, both Fatima and Cathy's children seemed to be placed lower on the spectrum, which means they might need more support. Anne's daughter can be placed on the opposite side of the spectrum. Her behavioural traits did not present as severely; therefore, she would require less support. The spectrum and the possibility of co-morbidities assisted in assessing what support was needed from the parents, family, and community.

Although ASD seems to be identified as a Western concept, the behaviours observed by the parents reflect universally and seem to be common across all cultures. The concept of the continuum also allows space for various traits to be incorporated from different cultures. Stone-Macdonald and Cousik (2016) support the statement by saying that "autism is truly a spectrum disorder, not just in the level of severity, but also in the symptoms that are most commonly observed in different cultures" (p. 96). Thus, it is important to mention that the established Western-focused diagnostic criteria should be only a guide, although there are still overarching, common impairments that continue to be present across cultures (Wing, 2002). This links to Berry et al.'s (2002) study that proposes to identify "culture-common aspects of psychological functioning" that could be found across different cultural contexts, as it facilitates support and understanding in communities (p. 332); more specifically, with the goal to reduce stigmatisation and vulnerability of the children in the community.

4.3.1.2 Theme 2: Making Sense of their Child's Behaviour

Theme 2 encompasses not only how the mothers experienced their children's explicit behaviour daily, but also describes their reactions to it. The theme is divided into three subthemes: (i) reluctance to accept ASD diagnosis; (ii) limited knowledge of ASD; and (iii) reaction to their children's uniqueness.

i. Reluctance to accept ASD diagnosis

Amidst the awareness of their children behaving differently, all the mothers showed reluctance to accept the truth, and avoidance took its place.

I wanted to give myself some time to accept whatever is happening, because I already said that, ah ah, something's not right. So, they said I must go to (the hospital). So, I didn't go, I take my own time again and then I decided to do this Googling thing and then after that I go to (the hospital). [Fatima]

It could perhaps be argued that Fatima went through either a phase of denial or that she had not yet been educated about the manifestation of ASD. Anne explained how she started to suspect something was different about her child at the age of five, and yet still refused to believe what the nurse was telling her.

Come, we can take you through the procedure. I'm like, what procedure? I have a normal child, there's nothing wrong with my child. [Anne]

Later in the year, when her daughter was diagnosed with ASD, Anne still could not accept the diagnosis.

Then he said it on the spot, this child is autistic, and I was like, there is no way. There's totally no way that I have an autistic child. This child can talk, this child can read. [Anne]

Being in denial seemed to have caused a delay in diagnosis. The mothers' *personal* characteristics, specifically *force characteristics*, limited them in initiating the steps to finding a diagnosis. As stated in Gray's study (2002), a delay in diagnosis could encourage stigma or misunderstanding by the community. There seemed to be confusion about the 'typical-normal' physical appearance of a child, and then the 'odd,' disruptive and socially inapt behaviour of ASD that endorses the lack of acknowledgement of a possible ASD diagnosis.

ii. Limited knowledge of ASD

Although the mothers were able to identify the tell-tale signs of ASD, they initially had not heard of or experienced ASD as a concept in their communities – it was unknown to them. There seemed to be limited awareness of ASD and how it can manifest.

So that time I didn't understand what is autism. Is it a disability? What is going on? Like what now? Where do we go from now? What's going to happen? So, if the child is autistic,

isn't the child disabled? Isn't the child be able to talk? But my daughter can talk, my daughter can do everything, anything. [Anne]

Anne explained how it was labelled as a 'white people' concept, foreign to the black people.

The other autistic children in our culture, we associate it with maybe white people. No, it's white people who has autistic people or autistic children [Anne].

These beliefs of the macrosystem seemed to hide the truth of her child possibly having autism, although ASD symptoms seem universal and can be found in the Xhosa cultural community. ASD does not seem to be labelled or understood as a neurodevelopmental disorder. This differs from the perspective of the Western community, or as Anne said, the 'white people' (Mthombeni & Nwoye, 2018). Berry et al. (2002) support Anne's notion, by explaining that knowledge about ASD has been defined mainly by Western areas and people. Other ideas and reasons seemed to be provided to understand the child's behaviour.

Fatima related her experience of her son's behaviour to beliefs of the African community in which she had grown up. She believed that due to her being pregnant with another child, less attention was given to her son with ASD, and thus, it caused a delay when the child was five years old, turning six.

So, as the time goes on, the speech, like stopped talking and then I got pregnant with the other one, so I say, maybe just because, 'cause you know African people say that if you have a child while the other one is still young, so it can stop things. [Fatima]

Fatima received a formal diagnosis for her son only when he was six years old. The delay in diagnosing her son, caused him to attend school later than required. He started school only when he had already turned seven. The role of time, linked to Bronfenbrenner's chronosystem, can be highlighted here. The time at which the diagnosis was made and the mother accepted it affected her son's schooling and extent of support. In Guler et al.'s (2017) study, they found that many parents were made to feel blamed for the way their children developed. It was

similar to how Cathy felt, due to the community's comments about her child's lack of socialisation in the community:

Well, at the beginning, it looked like I was to blame because we used to stay in like areas in flats, apartments. So, you know, how it is…so it's my fault that she doesn't talk she just needed to be with other children. [Cathy]

iii. Reaction to their children's uniqueness

The subtheme assists in understanding the parents' reactions to the ASD diagnosis and how they integrated this new information with their meaning-making process. Each mother sought a unique way of understanding ASD and held on to that explanation or description. Although Cathy did not fully understand the extent of ASD or the complexity of its causes, she described it as follows:

But when I make it easy for me, it's just, I just says there's something within brain that doesn't connect. [Cathy]

I understand that, that your child, is not 100%, she develops slow than the normal children her age. [Cathy]

This is the way she is. She doesn't like being around people for a long time; she keeps to herself. [Cathy]

Both Cathy and Fatima clung to the explanation that the doctor provided:

So, she said, in terms of your daughter, her mind is for a 10-year-old. That time she was five years – she was four, turning five. Her mind is of a 10-year-old, that's how intelligent she is. However, in terms of communication, so she was five, turning six, her communication level is for a 3-year-old. So, there's not balance there. [Anne]

Their mind is like, when you put the plug on the electricity and then you take- sometimes it is like this … sometimes when they are in – they don't want to talk to us, let them stay

like that because maybe their mind is doing something – I don't know. So, their mind is like this, it's coming out and then goes in. [Fatima]

Their mind is not like other people, like other normal people … they say Leo is nine years but him, his mind is a 3- or 4-year-old child, so you cannot compare him. [Fatima]

The concept of ASD was unknown to the mothers initially. It seemed to be something that they were not accustomed to or taught about. According to researchers like Guler et al. (2017), Chambers et al. (2017) and Mthombeni and Nwoye (2018), there seems to be a need for further knowledge about ASD and acknowledgement of its presence in sub-Saharan Africa, specifically in South Africa.

Two studies, completed in Kwazulu-Natal in South Africa, focused on Zulu-speaking parents who had children with ASD (Chambers et al., 2017; Mthombeni & Nwoye, 2018). Their aim was to explore the African view, understand the culture; as well as the presence and influence of the caregivers on their child with ASD and their potential future (Chambers et al., 2017; Mthombeni & Nwoye, 2018). The findings indicated that knowledge and awareness of ASD were inadequate, which could have led to difficulty in recognising the possible signs of autism. Perhaps, if the parents from my study were more educated about ASD, they would have felt more capable to cope, and the children and the families would have received more support at an earlier stage.

1.3.1.3 Theme 3: Protective and Risk Factors

Theme 3 was divided into two subthemes: protective and risk factors. It illustrates the role risk factors and protective factors play in influencing their perception of ASD, as well as their capacity to take care of their children. The subtheme of protective factors describes the acceptance and resilience that took place when the mothers found out about the ASD diagnosis. The subtheme of risk factors refers to traumatic events the parents had experienced, as well as the potential effects of the events on their caregiving responsibilities and their concerns about their children's vulnerability and future.

i. Protective factors

While the mothers did not always understand ASD or have knowledge of the complex nature of the causes and how symptoms could manifest, all of them eventually came to terms with the diagnosis and accepted it. They understood that their children were and would be different from other children.

I still don't really understand it. Like, because there's no, there's no explanation because there has to be something. You did this. That's why it's like this, but there's no, like, proper explanation or so; I still don't understand. [Cathy]

I don't understand, but I have accepted and I'm living with it. Yeah. So, it's something that you just have to accept. [Cathy]

When Anne explained her daughter's diagnosis to her family, she told them that they needed to accept that she was different from other children.

So, I just told them, listen, you just need to understand her, don't be on her case or whatever, just try to understand that she is not like other children. [Anne]

Even though all the mothers had come to terms with the diagnosis, they expressed how difficult the process of acceptance was, but showed resilience by considering what their options were and what support they could find.

I'm not that kind of person – I'm a very stubborn person – as a result, I'm stubborn but I accept, I accept. I won't go like crazy and take myself and throw myself in the train station. I just sit and then and think what is the next option, what am I going to do? [Fatima]

Anne and Fatima both tried to learn more about the disorder and advance their knowledge and by doing that, equip themselves to understand ASD better. They used their force characteristics to activate the proximal process to provide ongoing support for their children with ASD. In Kapp and Brown's (2011) study, the participants found that acquiring new knowledge and skills helped them adapt to the presenting situation more easily.

I then had to Google like to search, okay, there were workshops that they were happening in _____, there were workshops that were happening in _____...so I told myself, let me engage, let me grab this opportunity, let me go join them to see what is going on. [Anne]

After people in Fatima's community and family misunderstood her son, she decided to read up on ASD to gain more insight.

I read and then I put it here in my mind. [Fatima]

The mothers showed endurance during the difficult times and kept moving forward, creating hope for the future.

We want to fight for her to be fine. We want her to have a normal life – we believe she can have a normal life. But we just need to keep going, keep encouraging her and keep teaching her. [Cathy]

Ya, we do speak sometimes but we don't dwell on it, feel sorry for ourselves. [Cathy]

It has made me realise that there's nothing that doesn't have a solution. Each and every problem – it has a solution because that time I even had suicidal thoughts because I was like, so now that means I'm failing this child and if I'm gonna have a normal, a not a child that is going to go to a mainstream school – this child is not normal, so what now? [Anne]

In a study that explored the resilience of families adapting to ASD in South Africa, participants shared that "accepting their child's diagnosis and reframing the situation contributed to their resilience" (Kapp & Brown, 2011, p. 461). Walsh (cited in Kapp & Brown, 2011) advise how important it is for the parents and/or family to accept the diagnosis, in order for them to normalise and contextualise their experience, and therefore make meaning of it. The process of making meaning would facilitate gaining support from those around them and at the same time provide understanding and support to their own children in the community.

ii. Risk factors

It was evident that the parents had experienced trauma and other difficulties in their lives along with their children's diagnosis. All of them had experienced the death of a close family member.

> *Because in 2013, I lost my father – he was stabbed to death … And then in 2016, then my brother fell at _____ then he passed away. [Anne]*

> *And this is my mother who died [pointing to the 'River of Life' drawing below] – just to show her dying … And that's when the river started getting difficult and difficult. So, this is just a side of my river that was curvy. [Cathy]*

Cathy's 'River of life' drawing

The exosystem interaction that occurred here, indirectly influenced the mothers' children with ASD in the care that they were able to provide. Bronfenbrenner emphasises the important role of the exosystem where it determines "whether parents can perform effectively within the family depend[-ent]on the demands, stresses, and supports of the workplace and extended family" (Rogoff, 2003, p. 47). In this case, the experience of loss in the extended family and

the effect thereof on the emotional well-being of the mothers and their caregiving responsibilities is clear.

Another prominent theme was that the mothers were stressed and worried about the safety, well-being, and future of their children. They were aware of the vulnerability that came with living with ASD.

Anne's 'River of Life' drawing

I couldn't cope anymore, so that's when I started to going there (hospital), that like that was a wave coming on to us [points to 'River of Life' drawing]. So, I was drowning – I couldn't understand like I was not coping. I stayed for two months out of work because I didn't know what to do … [Anne]

It got me thinking about her future, what's going to happen to her when I'm not there, whose gonna take care of her? Okay, so, I still think about those things even now, especially because we're not a big family. I don't have a mother, because maybe if my mother was still alive, she's gonna take care of her when I'm not there. It changed my life

because I worry about the future. So, I constantly worry, I constantly plan, like I have to buy a house, I have to save up some money just in case she can't work, I have to, ya, I have to think, I think about them all the time. [Cathy]

Because I was afraid people would take chances, you know? She so quiet, she, will, you don't think, you know people, they like to take advantage, like in terms of rape, in terms of everything. So, you have to then make her aware, listen if someone touches you here, you tell me. If someone did this to you, you tell me. If someone does something that you're not comfortable with, you tell me. [Anne]

The fears the mothers were experiencing align with available research. Fisher et al. (2013) found that people who lived with ASD were more likely to be vulnerable to bullying and forms of abuse. Barrio et al. (2018) claim that children with ASD have difficulties with belonging in their cultural context. Additionally, any misunderstandings or unawareness of the culture and its practices about ASD could lead to more feelings of rejection and ineffective support (Barrio et al., 2018).

Fatima and Anne commented on their concerns about future schooling. They had not been informed or did not know of any other schools or facilities that their children could attend.

Where are they gonna go moes? They not going to go, after those phases – they're not going to go to _____ [school]... So, the worry was that was where are they going to go? [Fatima]

They say the list is long, but now, okay, but it triggered my emotions because I was like, okay, Alice still young, let me not worry about it for now, but then in the future, what will happen? That's high school, ah, okay, but then after high school – what's going on? So, is there a tertiary institution for them? [Anne]

I asked if they would like to receive more information or be educated around the subject, and they responded as follows:

Yes, yes ... like I need more, I need to be educated more, because that was a question I've been asking myself, but then I didn't know who to ask that question to, you see … So, having children that are not, are autistic in their disorder, in the spectrum, so now we need to be prepared of the outcomes, what will happen that in the near future? So that we can plan properly, you see. [Anne]

Both Anne and Cathy hoped for their children to have a better life than they had experienced, which motivated them to work even harder to support their children.

When you are pregnant and you give birth to a child, you literally have plans like, okay, I'm going to take my daughter, because now my daughter will have great future and then like … because I went to the township schools … So, I wanted my children not to experience what I've experienced. [Anne]

I want to give them the life that I never had. I want to make sure that they are fine – even when I'm not there … that's what I'm living for. [Cathy]

The mothers' interactions with their children's behaviours and how they dealt with it in their context, and at the time, resonate with the bioecological focus. Bronfenbrenner's bioecological model highlights how the proximal processes, namely the interactions between the environment and the person, are dependent on the varying factors of the person, the immediate and more remote context, and time periods in which these interactions take place (Bronfenbrenner & Morris, 2007).

The parents would be placed within the children's 'circle of influence' (Bronfenbrenner & Morris, 2007). Representing each parent is the parent's sociohistorical context, involving the parents' family, friends, and community, which includes their cultural beliefs, traditions, and values. The parents' personal characteristics, like traumas, emotions, attitudes, personality, potential for resilience, and personal experiences, all contribute to their meaning-making of ASD (Hebert & Koulouglioti, 2010). Thus, it helps to understand how the parents make meaning of their lives and assists in understanding their experience of ASD.

The way their children with ASD interacted with the world, gave them an idea that their children were not like their peers. Personal characteristics played a vital role in assisting the mothers in noticing that their children were developing differently. Both Anne and Cathy seemed to have *resources* like developmental knowledge and experience that helped them to identify that there was a possible difficulty. It is important to note that in both cases, the mothers – not anyone else – were the ones to realise their children were different.

In all the mothers' narratives, it is clear that all of them made sacrifices for their children with ASD and committed their lives to supporting them further. Their acts of resiliency were identified as a protective factor for the families which assisted them in coping with and caring for their children. The parents' traumatic events and stresses about their children's future presented as risk factors that seemed to have hindered the process of early diagnosis and support for their children. Even so, in both Cathy and Anne's 'River of Life' drawings, it is evident that there is a change from difficult times to more enlightening, positive times.

4.3.2 Knowledge and misconceptions of ASD in the community

The following themes and subthemes relate to the knowledge and misconceptions of ASD in the Xhosa community (secondary question 1.3). To truly understand the experience of Xhosa-speaking parents that care for children living with ASD, the ecological niche is an important aspect to consider; that is, the community and culture in which the parents find themselves. Factors in the ecological environment and subsequent interactions have the power to inhibit and/or cultivate healthy caregiving for a developing child with ASD. Therefore, it was important to analyse the perspectives of the community and to what extent they possibly influenced the parents' care and support for their children.

4.3.2.1 Theme 4: The African Community

Theme 4 is divided into two subthemes, namely (i) African beliefs and (ii) spirituality of Africa, which encompass important components of the community that seem to maintain its functioning. The spirituality dimension plays an important role in influencing community

members' beliefs and perceptions that in turn direct the actions taken by the people in the community, for example seeking support. Even though spirituality forms part of the African beliefs, the significant role it plays should be highlighted. The parents as participants of the African community described how they believed the community perceived ASD. According to the literature review in Chapter 2, it was found that Africans believe that the community best functions as a collective, as one (Berry et al., 2002; Botha & Moletsane, 2017); therefore, the parents' voice reflects the beliefs of the community about ASD.

i. African beliefs

Although the parents believed that ASD was real and existed as a neurological disorder, they alleged that the African community itself did not truly understand or support its prevalence among its members. The parents commented on the fact that many of the African people viewed ASD as an illness and not as a neurodevelopmental disorder. For the community, this meant that there was something wrong with the person's mind and they should be treated differently, like outcasts. Being labelled with a mental illness by the community seemed to have a negative connotation, as it ended in early judgement, which often led to bullying behaviour.

> *Mental illness like so, for instance, for her that will look inappropriate – like the things that she does that are unacceptable behaviour. Like for laughing while she's walking alone, you know, it's only mentally ill people who does those things. Or just the facial expressions. And the hand gestures, sometimes she has that but not a lot. But the point is that they won't, like autism, it's not, it falls under a mental problem. [Cathy]*

> *It's not nice. It's not nice because even mental illness, the most negative things in our communities, like mental sick, oh, just leave that person, because he or she is mentally ill. There's no like there's nothing that you'll get from them. Yeah like that's not a nice feeling. [Cathy]*

So, there was this one time and she came back and she said that the children are mocking her. [Anne]

The label of a mental illness by the community also seemed to influence the early identification of individuals and subsequent diagnosis of the disorder. Two of the mothers spoke about their reflections about growing up in a community that adopted the African belief of ASD as a mental illness that stemmed from the spiritual realm and how they believed, already back then, that they grew up with children who had ASD. However, with an increased awareness of the traits and common behaviours associated with ASD, the parents can more readily identify a rising prevalence of ASD in their community.

They've always been there when we're growing up, they've always been there – it's just that we just didn't know. We thought it's because, mental illness or something, but really when you think about it … we grew up … big size, like she has [referring to her own child], like not talk, but be by themselves, and like have some facial expression, they'll do like facial expressions and we thought it was just a mental issue. No what I understand and know about autism – I think it wasn't. [Cathy]

Because when we grew up, we had someone in our community, when I grew up, she was with us, she used to struggle with everything, shame in class like in writing and whatever, but then her parents let her continue in a mainstream school, up until to a certain grade and then she stopped, she stopped going to school. [Anne]

But with us, black people – autism is something that is common, but we don't understand, in our community, but we don't really understand it. [Cathy]

There is autism, and autism is more in our black community now. But they are in denial – we do not wanna disclose, do not wanna diagnose our children. [Anne]

We had that belief, in our culture, in our community, we do not have a child that is autistic, we do not want to accept that. [Anne]

Anne spoke about the community being in denial and not wanting to accept that the child possibly might be diagnosed with ASD. The community associating the child's behaviour with a mental illness seemed to aid the denial process. In a study in both South Korea and South Africa, where ASD was underdiagnosed, it was found that people shared ideas and practices in their culture that informed their way of thinking and meaning-making of ASD (Grinker et al., 2012). Collectively, members of the Xhosa-speaking community have implicit ideas of what and how they believe the person needs to develop and what the cause could be for observed differences. Rogoff (2003) agrees that the "goals of human development vary considerably according to the cultural traditions and circumstances of different communities" (p. 18).

The parents were challenged by the community's ideas and beliefs, which seemed to create a process of denial among the parents (as seen in Theme 2), which in turn delayed support for their children with ASD, as well as for themselves. Although this was an obstacle, they were able to decide independently what to believe about the diagnosis received from the health professionals. Even with the acceptance of the diagnosis of ASD, it seems that not all the parents understood ASD and how it manifested. It led to questioning about what to believe when it came to the potential causes of their children's behaviour.

> *I would like to know why. What did we do or something like that, but obviously get to those answers now. [Cathy*

Cathy explained how the community thought that her child's behaviour could either be because of a developmental delay or due to lack of interaction with other children of her age. Cathy describes how she used to stay in an apartment and not in the township, and how people would say that her daughter could not speak because she was not exposed to playing with other children, like the children playing in the streets in the township.

> *Well, at the beginning, it looked like I was to blame because we used to stay in like areas in flats, apartments. So, you know, how it is … so it's my fault that she doesn't talk, she just needed to be with other children. [Cathy]*

Maybe I did something wrong when I was pregnant, I don't know. [Cathy]

All the wondering about the reason her child is different caused Cathy to want to blame herself. She seemed to feel more vulnerable while being influenced by the comments from the community, which caused her to stress. Additionally, the community seemed to believe that there was nothing wrong with the child based mainly on the child's physical appearance, her demand characteristics.

So, they said she'll be fine, she just needs to associate with other kids. Like they don't understand that it's a condition if there's nothing she won't be fine with. But I've gotten use to such comments, no, she's just need get used to people and all that. So that's, that's the comments from my community. No, we don't see anything wrong with her. She looks fine. [Cathy]

I just thought it was like … Since we don't know much about autism or believe in autism, So I went with what other people were saying – maybe she's just a bit delayed, you know, it happens. My child spoke when she was five years. So, I thought it was just a delay. [Cathy]

Other beliefs in the community that seemed to influence the mothers' perspectives were related to the importance placed on the role of the father in the community. Anne explained how there was a risk that a father would not accept a child that could possibly suffer from a mental illness or who is different to other children. Anne's partner and father of her child was told about the ASD diagnosis, and confirms her belief in that he seemed to reject the notion of the concept of ASD. This could either be that the father was in the emotional phase of denial, or that he was uneducated about this disorder, struggling to integrate his traditional African beliefs, especially with regard to the mental illness concept, with new information.

So, if you guys don't want to accept and don't want to understand how she is, then that's fine – as times go by, but I, we understand. If then, if the father, because also in our community – we have that thing when the father, when you say, I have a child that is not

normal, and then the father will be, will act different or whatever … nothing has changed ... Autism is a disorder, but then to me, my child is normal. And then I was like, okay, that's fine. [Anne]

Fatima alluded to the important role of the father in the community. She referred to the African ceremony, *imbeleko*, which is the process of introducing the child to the father's ancestors, which forms part of the spirituality dimension. Traditionally, this occurs if you are unmarried and your child has some challenges, then the ceremony needs to take place. However, Fatima did not seem easily influenced by the beliefs of the community. The community believed that the child was not speaking because she had delayed the process of introducing her baby to the father's ancestors.

We African people have got those belief: man, the child needs to do things there by the father's side and all that and all that. [Fatima]

No, other people they use to say, no you must take this child to sangoma and all that because, how come the child speak and then all of a sudden like the speech ... [goes away]. [Fatima]

In summary, beliefs in the *macrosystem* that are constantly perpetuated in microsystems like communities, neighbourhoods, and homes may be identified as risk factors for interactions in the mesosystem. This could lead to the forming of negative or unhealthy processes. The unhealthy process that seemed to be evolving in the community of the participants in this study and their children was the continuing cycle of stigma and discrimination against them. In Gray's (2002) study, factors that seemed to perpetuate the cycle of stigmatisation was the delayed process of diagnosis or a lack of diagnosis, which was related to a limited understanding of the manifestation of the disorder and what it meant. This seems to resonate with the current study.

ii. Spirituality in Africa

The spiritual realm, also called the meso-cosmos, plays a vital role in the lives of Xhosa-speaking people. In the spiritual realm, chance and the spiritual forces of the ancestors, evil spirits, and sorcerers take control (Viljoen, 2003). The ancestors' role is to intercede for God and communicate to the people, as well as to take care of and protect their relatives. On the other hand, the sangoma adopts a mediating role between the people and the ancestors (Mokgobi, 2014). The belief is that the spiritual realm affects one's well-being; therefore, the assumption of the community is that a person with ASD could be seen as being cursed (Guler et al., 2017). Thus, many Xhosa-speaking people associate conflict, illness, and death with the meso-cosmos, which then seems to influence their behaviour and way of thinking.

Fatima's family seemed to understand that there was something wrong in the family's spiritual realm that needed fixing. The community suggested that the child might have demons and that was the cause of her child's behaviour. Fatima shared a story about her mother who encouraged her to go to church so that her child could be healed, possibly from other demons. She showed reluctance towards this notion.

Researcher: How you grew up – how were your African beliefs?

Fatima: Ya, now, we are like, how am I going to say this now [mumbles] ... yeah, we do believe too much in those African beliefs, but even to church.

The other day my mother take me to another church ... Let's go to that church, there's this pastor there that is praying for kids and all that ... I mean for people. I say I don't want to do this, but she keeps on forcing to go. I say, okay, let me make her happy. I took my child with her and then we go there, and then yeah, this pastor came and prayed to us like, like there's nothing happening here, there's no demons here. It's just that in my childhood like this, it's born like that, or he changes to this. But you mustn't think that you're going to take out some demons or satans and that is happening to us ... and then we just go home, and then I didn't see anything because I don't believe in those miracles

that are happening, but as time goes on, I didn't even go there, 'cause my child is just not that kind of a person. [Fatima]

When Cathy was asked what the community believed the cause of a mental illness was, she also explained that they related it to demons.

Cathy: Demons, something like that, that's how it's taken – you have Demons.

Researcher: And do you also believe that with your child?

Cathy [laughs]: No, no, I don't believe that at all. I know there's something wrong with her, but I don't believe it's demons.

The quotes mentioned portray deep African beliefs and traditions. Mtuze (2004) comments specifically on the cultural Xhosa beliefs of "when illness occurs within the community, they regard this to be the doing of the 'evil-minded'" (p. 69). He adds that some people from the Xhosa culture seem to believe that mostly evil forces could cause harm to the individual and that humanity is born healthy and without any 'faults' (Mtuze, 2004). Fatima and Anne spoke about the Xhosa community believing in the concept of witchcraft.

Fatima: No, other people they use to say, no, you must take this child to sangoma and all that because, how come the child speak and then all of a sudden like the speech, no there is better stuff and all that.

Anne: They believe in witchcraft ... When something bad happens, we always associate it with witchcraft.

Fatima: Exactly … And then I'm like, let God do his part. I'm not that kind of person. I know that there are things like that, but if you put your mind there, you won't look on the other side. I'm gonna look on this witchcraft side and then I'm not going to focus on_____.

Anne: I was literally crying and I looked at my daughter and I'm like, God, did you do this really to me? So, I was able to then say, things will be fine man, like just have faith and whatever.

Both Fatima and Anne still seemed to believe that their lives were controlled by God, and they believed in him having an influence in their lives, which also relates to the core African beliefs. Here, we can see that, although there is a continuous process of participation in cultural activities, the person as well as the community can adjust and change (Rogoff, 2003). The knowledge and awareness of ASD traits seemed to empower the mothers to separate what they had learnt from what their communities with African beliefs had claimed ASD could be. The mothers were able to become independent from some of the traditional African beliefs that seemed to dismiss ASD and were able to introduce and incorporate the livelihood of ASD with their community.

4.3.3 Support and understanding in the community

In Guler et al.'s (2017) study, it was found that interpersonal and community support was an important factor that contributed to the parents' ability to cope. Reduced community awareness of ASD was one of the reasons for limited support (Guler. et al., 2017). Therefore, this study intended to explore how parents received support to manage the challenges and their emotional and psychological stress that came with caring for a child with ASD. Two main themes were identified that related to this, namely (i) family support and (ii) community support, which shed light on Question 1.4.

4.3.3.1 Theme 5: Family Support

The parents valued the support from their family and seemed to receive the most support from family members. Even though the parents had to explain ASD to their families, the families seemed to accept their children as family members.

My sister, my two sisters, because I've got two brothers and two sisters, so those ones are the ones who are [supporting], even now. Because my mother is old but she loves him. When I'm not there, she knows that she must look after him. [Fatima]

With the support, because my baby daddy was there, like through all, even though I was in denial, so then he came to terms, no, to us the child is normal. So, despite what they

are saying there is nothing, nothing changes, and with the support of my mom and my sister and my niece because they are always there, they support her, they are always with her throughout. [Anne]

Researcher: And how are they doing with understanding her?

Anne: They do, they do understand, even though sometimes I then feel like, no, no, she's crossing the line now – this is too much. Guys, you, don't let her do things that you see that this is not on, this is not appropriate for a child, because now she is abusing it, because she knows that she will let her get her away with everything so please do not let her. [Anne]

Cathy differed in that she felt limited support from her family and wished that she still had her mother with her to help. The information above resonates with Guler's et al. (2017) study, which reported a lack of awareness from the community, and in this case, families too.

Researcher: Okay, I understand. And so, how do you find your support? What is your support?

Cathy: My partner, that's the only person and my siblings. Just by talking and getting advice from them, because also there's nothing much they can do. But my partner supports me, talking about things and helping each other. It's only us.

And my family … its only me, and my brother and my sister; so, we don't have a, we're not a big family. So, no one is – the extended family, they don't even check in or they don't care. Okay. So, I don't, I don't really get like a lot of questions. What's going on? An update of her. [Cathy]

They could support me more. That's what I wish. I didn't really expect them, but I wish, let's say I just need a day for myself and someone will understand and just or maybe without me even asking – just think, shame she must be struggling, let me just go and leave my things, and let me go help and maybe she can have a day to herself … like there's not really support where you feel like she understands, like they don't really

understand. Ya, they know – you've explained to them that this is the issue, but still, there's no sympathy. [Cathy]

4.3.3.2 Theme 6: Community Support

The theme of community support is divided into two subthemes, namely (i) expectations of the community and (ii) resources available.

i. Expectations of the community

The parents seemed to leave an overall impression of not expecting support from the community. There seemed to be mistrust of the community. Yet, the overall consensus was that they would desire more support from the community.

It was clear that the mothers felt uncomfortable talking about the support they received from the community. They seemed to have different meanings of how the community was represented.

Cathy mentioned how the community had trauma of its own, and that it seemed almost selfish to expect help from the community.

Ja, they did, but people are busy with their own lives. Like they do support where they can but not like it's not the same anyways. The support you getting from people who are limited to community to the support you were gonna get from your own mother. [Cathy]

No, people are just having their own problems. I don't think they'll ever have time to support me. We just don't have time to share what's going on next door, especially in the townships. They are just worried about their own lives – it's even worse for us with special needs kids. But you can't blame them or want their support – you're not their main focus. So, you can't expect that from the community. [Cathy]

Fatima seemed undecided about the support she wanted from the community, although she still believed the community could support her more.

Researcher: So, do you find that you've had enough support from the community?

Fatima: I can't say enough, just a little bit.

Researcher: So, what do you want from the community – to have more support?

Fatima: ... noo ... I can't say. I don't know, because, no, I don't know, no nothing because I'm always like – as long as when they see him, that he's not doing the right thing, that is the best that they can do. Other than that, I'm fine.

Anne believed her child had not been exposed enough to the community for her to expect support from the people in her neighbourhood. However, she had found support from her friends in her personal community.

So, in terms of community, mmm, where I live she doesn't play outside. So, I think, like most of the people in the community, they don't even know she's autistic, because she only goes out when she goes to the shop and then she goes and buys whatever and then she comes back. [Anne]

Researcher: But they still show you support – your friends?

Anne: Yes, they do, they do. They like her a lot.

ii. Resources available

Although there seemed to be limited support from the community itself, it was found that in the wider community, they received sufficient support. Their surrounding resources, like hospitals, clinics, and health care workers seemed easily accessible and well informed. All the mothers were able to receive an accurate diagnosis for their child.

I go to all those sessions in _____ [hospital] and they wanted to check if he is speaking and that he can hear and all that. So, the doctor, later on as I was always going there tell me that, your child is, got autism disorder. [Fatima]

So, we, I asked the nurse at the clinic or when they asked me like, the stage in which the child was in – what was she is doing? So, I just told them that she doesn't have much, doesn't say, he hasn't said any words or what. So, they just referred me to a speech

therapist in_____ [hospital]. Yeah, that's when she was assessed speech therapist and then yeah, they do some test – hearing test. She can hear. That's where she was diagnosed. [Cathy]

While having a casual conversation with the nurse at the hospital about her daughter's behaviour, the nurse confronted Anne about her concerns.

Then she said, no, this needs to be well taken care of. Come, we can take you through the procedure. I'm like, what procedure? I have a normal child, there's nothing wrong with my child. Then now she said, let's call _____ Hospital to find out what's going on. Then she explained the matter to the person that was on the phone, and then now, we started the process. So, for me, that was a huge, a breakthrough for me. [Anne]

In Guler et al.'s (2017) study, the challenges that were found related to the interactions with the health care system, delayed diagnosis and treatment, lack of support, lack of awareness, and the influence of traditional medicine received. However, in the current study, an established, comprehensive, and supportive health care system seemed to be in place in order to confirm the diagnosis and a suitable school. In saying so, as discussed previously, there is limited access to high schools, and support from facilities for children with ASD after primary school. The mothers needed support in finding appropriate schools for their children.

So now I was also offered a new – there is a training or a programme that is a two-week programme. Then they offer the psych programme, then they offer this programme at_____ [school]. So, we did that, it's, I think two weeks, so we had to be there. So, they had to examine Alu[2] and then they, she has to be in class with the other children so they can monitor her and whatever. [Anne]

Then after that I go to Tygerberg and then Tygerberg they transfer me to _____ [school] for those tests that she [Anne said she was talking about, for like two weeks and then you did go there, because my concern now was, I want him to go to school. [Fatima]

[2] Pseudonym

Researcher: So, like the school, did you get the support you needed, when you found out that something was different about her? Did you want more?

Cathy: No, from like the hospital, no – I got the support that I needed, because they helped us. They even helped us placing her in a school, so, from there. No, I did not, they really did, and the sessions that we went for, they helped also. So, I got the support that I needed when I first discovered she's autistic.

Anne explained how she found support through the various workshops that were being offered in the area. This helped her with her process of understanding and accepting ASD.

So, when I went there, like with other parents, oh okay, so people are sharing their personal stories, what happens. So, their children are like screaming, they are shouting, they don't want to hear the sounds and then they don't understand, like that car passing, like you were explaining [said to Fatima]. Then I was like, oh, okay! So, then there are still some still on their nappies, they still need to be potty trained and whatever. So, I was like, oh, okay, so this is autism. [Anne]

Although the mothers received good support from the wider community, it seemed to have taken place over a long period (chronosystem). At schools and hospitals are waiting lists of children with disabilities who still need to be assisted.

Anne: They say government, they still struggling because this is a new thing that is being introduced now and the list is long and it can take.

Fatima: Ya, and they say that it can take about a year.

Anne: Now we were now left to see the neurologist. So, I think, there it took us 3/6, almost a year to wait for the neurologist because the list is long.

The above-mentioned statements indicate that the mothers were aware and seemed to feel that the government could do more to support children and parents who live with ASD. They felt the need to receive more education.

I think even our government – I don't know if they also don't understand or if they don't give too much attention. You see a lot of the attention is on people with physical disabilities like … but other people like autistic children … I don't think so. I think they also need to teach people more about such, not only for persons with physical disabilities. [Cathy]

Yes, yes ... like I need more, I need to be educated more, because that was a question, I've been asking myself, but then I didn't know who to ask that question to, you see. [Anne]

The aim of the focus group was to encourage the emergence of a type of support group of parents from the Xhosa-speaking community. Due to circumstances, not all the parents could attend the focus group. The parents still seemed hungry for this interaction. The mothers seemed comforted by knowing that there were other parents who were caring for children with ASD that were going through similar experiences as they were.

Sometimes you feel like, I'm lucky – okay I know it's a bad thing comparing other children but when you hear other parents, not complaints, but when they talk about their children and the problems they facing, you feel like, their minor problems. I don't have too much, I don't have it worse like other people. [Cathy]

When I joined all the groups on Facebook that have that, are parents that need support because of autism and when I read there – like I find out like a lot of mothers they are dealing with two children that are autistic and I'm like, I have one and then I'm complaining. Then they're not complaining, even though they feel like the load is too much, but they still carry on. Some, they even stop working, like it's their full-time job to watch over the children. So, for me, I was like, that didn't kill me, so it made me stronger to who I am today. [Anne]

One mother sought to connect with other parents who were also taking care of children with ASD. Both Anne and Fatima exchanged cell phone numbers at the end of the interview process.

Are you going to try to get more people because I think it will be interesting to know what's going on with them. Are they feeling the same way? [Cathy]

In conclusion, even though the Xhosa culture has a natural inclination to work together as a community and function as one, it was found that the mothers isolated themselves, and perhaps were also isolated by the community. This seemed to be due to their lack of awareness or knowledge of ASD. It seemed to delay the process of seeking support or a diagnosis. This started to cause stress in the mother's lives, and stigma seemed to grow. The community, and at times the family, seemed to defy the core purpose of their culture, which is to live in unity as one and contribute to their community.

4.6 Personal Reflections

I realised that the term *community* could be an overly broad term, and people's understanding of it could vary. For Cathy, her community of support was her partner and sometimes her siblings. For Fatima, her community of support was her siblings and her mother. For Anne, her community of support was her family, the child's father, and her friends. They did not seem to receive or expect much support from their neighbours and the people living around them. The other parts of the community could be extended to the macrosystem factors, like the hospital, clinics, nurses, and schools.

The 'River of Life' activity was used as a medium for discussion. I realised that the activity was very personal and emotional for the parents, and that it might have been difficult for the parents to express that genuinely in the research context. One participant, Anne, commented in Xhosa to the other participant, Fatima, how much the activity felt like a therapy activity, and she had been at a psychologist. This comment made me aware that the situation was intimidating for her. Although it seemed awkward for the participants, it really brought important information to the discussion and aided them in opening up.

4.7 Conclusion

The goal was to explore the experiences of parents who took care of their children with ASD in the Xhosa-speaking community, due to an underrepresentation of the Xhosa-speaking community. The parents were able to share the autistic traits that seemed to be common across cultures. They labelled their community as the “black/African people” and described an unawareness of the disorder, and how they as parents had to learn about this new concept called ASD. The mothers were able to integrate this Western idea with their traditional African beliefs and ideals and learnt to function independently. All the mothers agreed that they had experienced a lack of understanding from people in the community and did not expect to receive much support from them.

This study and discussion do not serve to represent the truth or the answer, but rather is there to provide a glimpse of insight into the lives of three Xhosa-speaking mothers who were given no choice but to take care of children with ASD. It inspires further researching of the experiences of these parents.

CHAPTER 5

CONCLUSIONS, LIMITATIONS OF THE STUDY, AND RECOMMENDATIONS

5.1 Introduction

The purpose of the study was to gain better understanding of the experiences of the underrepresented Xhosa-speaking community with ASD. To gain an intimate, more personal account of the manifestation of ASD in the community, the parents of children living with ASD were selected to communicate this. The importance of clarifying the perspectives of the community and their functioning regarding ASD, intended to contribute further to exploring what support and management was in place, if any, for the children with ASD and their families. The goal was to not exasperate the cycle of late diagnosis of ASD that would lead to rejection and isolation and a vulnerable future, but to prevent this from occurring.

This chapter will extend the discussion in Chapter 4 and integrate the findings with the literature, previous studies, and the bioecological model, which acted as a theoretical framework in the study. The chapter will conclude with the strengths and limitations of the research, and recommendations for future research will be shared. A section is also devoted to recommendations for support for parents caring for children with ASD.

5.2 Discussion of Research Findings

It was evident that the experiences of the parents had been influenced by the interplay of factors in themselves and their surrounding environment. To name only a few, factors such as their families, their interaction with the people in the community, the way in which they were brought up, the influence of African beliefs and traditions, and their exposure to the Western world were relevant. The period and timing of their experiences, as well as the consistency of all these factors, were also significant. Lastly, the resources of the community and ecological niche (environment), and their own resources, experiences, personalities, and abilities, played a role in influencing the parents' perceptions.

Bronfenbrenner and Morris (2007) explain how these processes – the interaction between the parent and the environment, as well as with others in the environment – have more or less influenced the parents' daily experience of caring for their children with ASD. Firstly, it depended on the personal factors of the parent, the child with ASD, the family, and other people in the community (Bronfenbrenner & Morris, 2007). Secondly, the factors in the personal environment in which the parent functions, as well as the more distant environment that surrounds and influences the parents' context, need to be considered (Bronfenbrenner & Morris, 2007). This is conditional upon the period within which the parents' experiences took place and is based on the (in-)frequency of the interactions between the parents and the surrounding inner factors (Bronfenbrenner & Morris, 2007). The power of these factors will be discussed next and be integrated with the findings of the study.

Bronfenbrenner's model assisted me in researching the functioning of the Xhosa-speaking parents by considering the parents not only as individuals, but also as parents who functioned in the contexts of the community and South Africa. Therefore, the study was able to assimilate the possible extent of influences of the Western culture upon the African community, determining the extent of the influence of the African beliefs and traditions.

The parents seemed to associate ASD with the Western world, as if it was something that did not fit in with their culture or community. Anne showed this understanding by saying that *"the other autistic children in our culture, we associate it with maybe white people. No – its white people who has autistic people or autistic children".* The limited exposure, or one could call it acknowledgement of the disorder, existing in their community could be attributed to the Xhosa-speaking community's beliefs and/or limited resources to inform the community of ASD. Instead, the community's beliefs and values were attached to the mothers' initial understanding of why their children were behaving differently.

Cathy explained how she was encouraged to believe that she was to blame for her child's limited social abilities because she was not exposing her to the children in the township. Fatima explained how she understood her child's development to be delayed due to the

community's belief that she seemed to neglect her child, because she fell pregnant while he was developing. Anne's partner denied that his child had ASD, as it was not a social construct that existed in his beliefs.

These parents clearly had been influenced by the context and community in which they lived, engaging in the macrosystem of embedded cultural beliefs and values, and the microsystem of family members and friends, where power is given to the 'circle of influence' with whom the parents interact, the mesosystem (Brendtro, 2006). Ravindran and Myers (2012) explain that a family's beliefs can indirectly influence how the child is accepted and found worthy, determining the amount of time and resources invested in supporting the child. This is dependent upon the family's expectations, and then essentially the parents' expectations of their child's potential and development. Sow (1980) describes this level of interaction as having a collective existence and occurring in the micro-cosmos (Viljoen, 2003).

To understand the parents' experience in depth, one first has to consider the perspectives of the macrosystem in which they grew up. The community perceived a child with ASD as either having a mental illness or having been brought up poorly, with limited engagement in social activities, or being affected by evil spirits. The result of these ideas permeated the parents' thinking and interactions with their children. This led to a process of denial which, also could be attributed to a lack of knowledge/understanding about ASD. If Anne and Fatima were more informed about the manifestation of ASD and realised that it was not met with discrimination or judgement from the community, they might have received support (for the parent and the child) at an earlier stage in their children's development.

Both Anne and Cathy mentioned how their children were teased and bullied for being different. The mothers had also experienced the rejection of other possible cases of ASD in the community, while they were growing up. These processes, which occurred in the mesosystem, had been imprinted over a long period, had been internalised by the mothers, and affected their perspective of the community. In a study based on the transition from childhood to adulthood, the parents believed that their children were being marginalised due

to their behavioural traits and deficit in social interaction (Thompson et al., 2018). Thompson et al. (2018) add that the parents suggested that the children with ASD were misunderstood and support was limited due to their typical physical appearance and no visible intellectual difficulties, which Bronfenbrenner refers to as person factors. The person factors of the people of the community, their macrosystem beliefs, and the interaction between these two factors over time have influenced the parents' understanding of how ASD is perceived.

Perhaps the stigma of a disability played a role in preventing the parents from discrediting the truth at an earlier stage. Gray (2002) calls this a coping strategy and describes it as the parents restricting incoming information about ASD and acting like a typical functioning family, in order to prevent stigmatisation. If the parents are unable to restrict this information, they cope by avoiding certain public situations or social interactions with their child. Cathy described that she had no friends and did not go out to socialise. Both Anne and Cathy initially denied the ASD diagnoses: Even once the information had been shared with them by a health professional, they decided not to investigate the diagnosis further for a short period. Gray (2002) mentions a term called "felt stigma", which relates to feelings of shame and rejection, even though the stigma has not necessarily been enacted (p. 737). It seems as if the fear of stigma potentially affected the parents' acceptance of the disorder. The cultural opinions associated with the Xhosa-speaking community seemed to exasperate this fear of stigma and acceptance of the disorder.

With regard to the above-mentioned fear of judgement, misunderstanding, and discrimination towards the mothers with children with ASD, the mothers perceived their children to be vulnerable in society. Van der Mark et al. (2018) found that African mothers in the South African context experienced abuse and violence towards their children with disabilities, which made them feel anxious about their children's safety. Both Anne and Cathy were also concerned about the safety of their daughters and wondered if their children would be able to stand up for themselves. Additionally, all the mothers were concerned about their children's future plans and how they would cope when they were older and hopefully more

independent. They were aware of their children's inability to function independently, and their difficulty with interacting in a socially appropriate manner. Volkmar and Wolf (2013) discuss the difficulties adults with ASD experience in living independently. Across studies, although an improvement has been seen over the years, there is an estimate of 50% of people living with ASD battling to succeed in the adult world (Volkmar & Wolf, 2013). Additionally, "there appears to be no research conducted with regard to adolescents with ASD transitioning to adulthood within a South African context" (Meiring et al., 2016, p. 2).

Consequently, it seemed as if the mothers retracted from the community that did not seem to understand and accept the diagnosis. In a study based in Khayelitsha, an African-dominated environment, it was found that the mothers took sole responsibility for taking care of their children with disabilities, had limited interaction with others, and became isolated from their community (Van der Mark et al., 2018). This was a similar experience for the parents in the current study. In their study Van der Market al. (2018) describe factors that possibly contribute to the mothers' isolation. The first factor that was highlighted, was the limited support from family, the community, and wider community, which forced the mothers to take responsibility for caring for their children (Van der Mark et al., 2018). Similarities were identified between these findings and those in the current study.

Since the mothers experienced limited understanding from the community, they did not expect much support from the community itself. Cathy understood the community to have challenges of its own to manage and that it could not be bothered with her and her family's difficulties. Although Fatima desired more support from the community, she did not depend on them for support. One could conclude that the community either experiences challenges of its own and cannot provide support, or that the community misunderstands or does not acknowledge ASD as a reality, being influenced by the values and ideals of its members. This would need to be researched further to accommodate and support the community. The mothers' endeavours of finding support in the other microsystems in the community occurred

inconsistently and was rare, which caused the mothers to change their attitudes (person factors) about expecting help from the community.

In contrast to Van der Mark et al.'s (2018) study, the mothers received support and guidance from the governmental institutions and wider community, the exosystem, and other microsystem interactions. The clinics and hospitals were accessible and showed understanding of ASD. Although there seemed to be support for a child at a young age, there is limited support for children with ASD as they move into adulthood. Howlin (2021) mentions that studies published by Taylor et al. (2014, 2015), and Chan et al. (2018) have "highlighted the lack and/or poor quality of provision for young people with autism once they leave school" (p. 3).

Although the parents had not heard of ASD before receiving the diagnosis, they were able to accept it eventually, attempt to understand it, and make new meaning of the diagnosis by integrating it with their families and community, and essentially African beliefs. Cathy explained how she did not understand ASD, but that she had accepted it and was learning to live with ASD in her life. Anne spoke about her mental health challenges and how she overcame them and sought help. Similarly, the mothers who participated in Van der Mark's et al.'s (2018) study were able to accept their children with disabilities and used this as a "life strategy" (p. 113). The Xhosa-speaking mothers were able to reframe the idea of ASD into their ideals and adapt accordingly (Kapp & Brown, 2011). Even though this "life strategy" that the mothers adopted was forced upon them due to their environmental factors (context), and the limited support, they were able to feel that they were in control (Van der Mark et al., 2018).

The mothers were able to identify behavioural characteristics that were consistent with the universal ASD traits commonly found across different contexts. This shows that ASD not only can be defined as a western disorder, but also can be related and exist in any culture. Even so, it can be difficult to form a diagnosis based on the varying behavioural characteristics, which range from mild to severe on the continuum. Some of the associated families were able to witness the process of acceptance and resilience of ASD in their family members' lives,

proving that ASD does exist, and that it is not related to mental illness or evil spirits, and that a better understanding of the diagnosis can bode well for a supportive environment. The new process that occurred between the mother with her child with ASD and the family, which had become consistent over a long period, influenced the families' perspectives of ASD, which aided their person factors to be adjusted and accept the idea of ASD existing in their community.

It is hoped that if more parents' knowledge and understanding of ASD is developed and the parents interact indirectly and directly with their families over a period, it will start changing the families' understanding of ASD. The families will witness the behaviours of the child, as well as the effective support by the mother alongside the commentary of the mothers' knowledge. If this process occurs with multiple families repeatedly and over a long period, the community's beliefs eventually will begin to change and be adapted. Ideally, the community's adapted beliefs will affect the bigger context, gain support from the macrosystem, and influence policy change.

5.3 Strengths of the Research

The interview environment, art activity, and guided questions in each interview were cohesive with the parents sharing their experiences openly. Therefore, the stories and understandings shared by the parents were descriptive and rich in detail. The study intended to give a voice to the Xhosa-speaking parents, and essentially the community. In doing so, I believe I have encouraged the beginning of better understanding of the Xhosa-speaking community and ASD, which hopefully will trigger further research to be performed.

5.4 Limitations of the Research

The scope of the study was limited to three participants from the Xhosa-speaking community. After several attempts to invite parents to participate in the study and efforts to accommodate the parents to the best of my ability, more than 8 participants responded, but only three parents saw the process through. Therefore, the first limitation affects the

generalisability of the findings. As seen in the findings, and in other limited research studies, there is a lack of knowledge and understanding about the manifestation of ASD in the African communities, specifically the Xhosa-speaking community. In consideration of the findings, it is evident that due to the lack of early identification of the diagnosis, it can be difficult to gather participants who know their children have a diagnosis for the study. Therefore, it was challenging for the researcher to find various research sites to access, where the parents were aware of their children's ASD diagnosis. Despite various limitations, the focus of the study did not aim to generally describe the Xhosa-speaking community of parents as a whole but tried to understand the subjective accounts and stories of parents caring for children with ASD.

A limited number of parents who arrived on the first and second days of data collection led me to change my data-collection method from a focus group to individual interviews. Hence, the second limitation is that the data-collection method would have been helpful with regard to accommodating the African view of collectiveness.

Thirdly, the COVID-19 pandemic and national lockdown regulations placed limitations on the accessibility to the participants. In the proposal-writing phase, a school in one of the Xhosa-speaking townships in Cape Town was approached to act as a potential research site. However, because the pandemic was still a new idea in peoples' minds, the principal was cautious and consequently declined the invitation to participate in my study. I had to find another research site that matched the inclusion criteria for my study, which regrettably had a smaller target population than the initial school had. The limited number of parents that agreed to participate could also be attributed to COVID-19 and the parent's fears about the pandemic. Additionally, the research site was limited because it was not situated directly in a community that mostly constituted Xhosa-speaking people. Had the latter been the case, it would have enhanced the strength of the experiences of the African beliefs, as well as the generalisability.

Fourthly, the pandemic also delayed the research process, as the University had to abide by national COVID-19 regulations to protect primary investigators, the participants, and society. The Research Ethics Committee (REC) of Stellenbosch University published position

statements outlining responsible and ethical research conduct during the time of the COVID-19 outbreak, by which all researchers had to abide. With more time, and by identifying an additional research site, more participants perhaps could have been engaged in the study.

Lastly, the differences between the cultural groups of the researcher and the participants, and the participants' awareness of this difference, could have limited the participants in expressing themselves more freely.

5.5 Recommendations

For the reason that the study had a limited sample, future research is encouraged, as a study involving a larger sample of participants may provide richer data.

5.5.1 Future research

I hope that the experiences of Xhosa-speaking parents who take care of their children living with ASD, can be further investigated. Firstly, it is recommended that a focus group on a larger scale be used as a research data-collection method. As mentioned before, the Xhosa community seem to benefit when working collectively. In the study, the mothers were eager to share their experiences and find support from other mothers who also had children with ASD. The focus group would allow and enable the participants to form and gain a support group in their community, without having to feel judged or ashamed.

Secondly, it is recommended that other researchers attempt to access more than one school to increase their target population and potentially the sample size of their study. Utilising social media is another alternative that can be explored to increase the target population. Social media can be used as a platform to access more people from the Xhosa-speaking community who care for children living with ASD. More people are communicating via social media platforms to seek support from online support groups, follow a profile to receive guidance, or to befriend others who are facing the same difficulties. Anecdotally, I am following various ASD groups on Facebook and Instagram and have found an overwhelming number of Xhosa-speaking parents reaching out to the community.

The purpose of the study was to understand how support could be provided for the vulnerable families that managed ASD. Possible ideas to incorporate support more realistically are discussed next.

5.5.2 Further support

This study aimed to increase the notion of supporting parents of children with ASD in a Xhosa-speaking environment, and essentially supporting the community as a whole. To support the community, in-depth understanding of the experiences of the parents will assist in aiding the development of an inclusive society for children with disabilities or developmental challenges. This means that there should be just and equal treatment of those with disabilities/challenges, which should form part of the socio-economic decisions and policies, and not be regarded as a non-entity (Van der Mark et al., 2018).

These policies and strategies, which in turn result in collective action, must be sensitive to the needs of the parents and the community and aim to provide care. Primary health care workers are encouraged to consider the experiences and the cultural values and beliefs of the parents and to adapt accordingly. As stated by Ravindran and Myers (2012); ”if a culture becomes more accepting of children with disabilities, a nation might pass laws mandating enhanced disability policies for early intervention, schooling, and employment” (p. 313).

It is important that professionals and society initiate the process of reaching out to these parents who have isolated themselves, gaining their trust. The parents then should be provided with a voice and be enabled to share their ideas and frustrations over a long-term period. Local health care providers can be trained to facilitate support groups for these parents where they can feel understood and gain their trust back from the community. It is important that mothers should be able to involve whole families in these support groups, and that workshops where training takes place be facilitated for the rest of the family.

5.6 Conclusion

The accounts of Xhosa-speaking parents' experiences in caring for their children with ASD have provided insight into the possible challenges and understandings of ASD in their community, as well as the well-being of the vulnerable children with ASD and their supporters. In essence, this creates repetitive or non-repetitive processes that occur in the community over a period and start forming the ideals of society as a whole. Therefore, it is crucial that further accounts should be heard and explored, so that appropriate support can be provided, thus allowing the parents to start trusting a supportive process and engage with the community positively, and to restore hope.

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APPENDIX A

DSM-V DIAGNOSTIC CRITERIA

DSM-V: Autism Spectrum Disorder

Diagnostic Criteria 299.00 (F84.0)

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures: to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

APPENDIX B

ETHICAL CLEARANCE LETTER

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

NOTICE OF APPROVAL

REC: SBER - Amendment Form

31 March 2021

Project number: 18998

Project Title: iLizwe lam (My world): Xhosa-speaking parents' experiences of caring for a child with Autism Spectrum Disorder

Dear Miss Sinead Comninos

Your REC: SBER - Amendment Form submitted on 09/03/2021 16:08 was reviewed and approved by the REC: Social, Behavioural and Education Research (REC: SBE).

Please note below expiration date of this approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
27 January 2021	26 January 2022

GENERAL REC COMMENTS PERTAINING TO THIS PROJECT:

INVESTIGATOR RESPONSIBILITIES

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: SBE, the researcher must notify the REC of these changes.

Please use your SU project number (18998) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

You are required to submit a progress report to the REC: SBE before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary).

Once you have completed your research, you are required to submit a final report to the REC: SBE for review.

Included Documents:

Document Type	File Name	Date	Version
Research Protocol/Proposal	Annotated Chapter 1_SineadComninos	09/03/2021	Word
Informed Consent Form	Final Consent form annotated	09/03/2021	Word
Default	Final invitation Annotated version	09/03/2021	Word

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Social, Behavioral and Education Research

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.

Principal Investigator Responsibilities

Protection of Human Research Participants

As soon as Research Ethics Committee approval is confirmed by the REC, the principal investigator (PI) is responsible for the following:

Conducting the Research: The PI is responsible for making sure that the research is conducted according to the REC-approved research protocol. The PI is jointly responsible for the conduct of co-investigators and any research staff involved with this research. The PI must ensure that the research is conducted according to the recognised standards of their research field/discipline and according to the principles and standards of ethical research and responsible research conduct.

Participant Enrolment: The PI may not recruit or enrol participants unless the protocol for recruitment is approved by the REC. Recruitment and data collection activities must cease after the expiration date of REC approval. All recruitment materials must be approved by the REC prior to their use.

Informed Consent: The PI is responsible for obtaining and documenting affirmative informed consent using **only** the REC-approved consent documents/process, and for ensuring that no participants are involved in research prior to obtaining their affirmative informed consent. The PI must give all participants copies of the signed informed consent documents, where required. The PI must keep the originals in a secured, REC-approved location for at least five (5) years after the research is complete.

Continuing Review: The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the REC approval of the research expires, **it is the PI's responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur**. Once REC approval of your research lapses, all research activities must cease, and contact must be made with the REC immediately.

Amendments and Changes: Any planned changes to any aspect of the research (such as research design, procedures, participant population, informed consent document, instruments, surveys or recruiting material, etc.), must be submitted to the REC for review and approval before implementation. Amendments may not be initiated without first obtaining written REC approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

Adverse or Unanticipated Events: Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the REC within **five (5) days** of discovery of the incident. The PI must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants.

Research Record Keeping: The PI must keep the following research-related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence and approvals from the REC.

Provision of Counselling or emergency support: When a dedicated counsellor or a psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

Final reports: When the research is completed (no further participant enrolment, interactions or interventions), the PI must submit a Final Report to the REC to close the study.

On-Site Evaluations, Inspections, or Audits: If the researcher is notified that the research will be reviewed or audited by the sponsor or any other external agency or any internal group, the PI must inform the REC immediately of the impending audit/evaluation.

APPENDIX C

INVITATIONAL LETTERS: ENGLISH VERSION AND XHOSA VERSION

Invitation to participate in my research project:

iLizwe lam: (My world): Xhosa-speaking parents' experiences of caring for a child with Autism Spectrum Disorder

Dear parents/ caregivers

Do you feel alone in your journey with your child with ASD (Autism Spectrum Disorder)?

Do you understand what ASD is?

Do you feel like your child is different to other children?

Are you struggling to connect with your child?

Do you feel like you are being supported by your community?

I would like to offer you the **opportunity to be part of a group discussion** with other mothers/fathers that may be experiencing the same feelings.

****NOTE:** **TAXI FEE WILL BE PROVIDED FOR**, to the school venue and back to your home.

This can be an opportunity to share:

- **your pains and praises**
- **your fears and hopes**
- **your story and thoughts**
- ***your support and worries* – within a safe space in your community.**

It will require you to:

- **be available for only <u>ONE</u> Saturday and be involved in two group sessions of 2-3 hours each.**
- **be part of answering questions and engaging in discussions about ASD and the community.**
- **take part in an art activity that requires sharing your life story.**
- **be honest and open**
- **sign a confidentiality agreement about keeping the group discussion and members a secret/private.**
- **Speak some and understand some English.**

Once the form is completed- according to your choice, you will be contacted and sent further information. If you have **any questions** or would like to have more information, please feel free to **contact** me:

Sinéad Comninos from Stellenbosch University
Currently completing Master's in Educational Psychology
Cell: 0832330457
Email: sineadcomninos@gmail.com
My supervisor: Carla Feenstra
Email: carlaf@sun.ac.za
Thank you for your time in reading this. I hope to hear from you soon.
Warm Regards
Sinéad

***PLEASE RETURN TO SCHOOL**

If this is an opportunity you would like to make use of, please fill in your name in the **green** box below (YES):

I accept this invitation:	
Cell phone number:	

If you **do not** wish to make use of this opportunity, please fill in your name in the **red** box below (NO):

I decline this invitation:

Please complete if you said YES, and tick the boxes below that are appropriate for you (Ö):

I understand and speak English well. ☐

I do not understand and speak English. ☐

I can only sometimes speak and understand English. ☐

My culture is Xhosa. ☐

My culture is not Xhosa. ☐

My child/ adopted child has ASD/ Autism. ☐

My child/ adopted child does not have ASD/ Autism. ☐

INVITATIONAL LETTER: XHOSA VERSION

ISIMEMO SOKUTHATHA INXAXHEBA KUPHANDO

iLizwe lam: (My world): (AMAVA ABAZALI ABANTETHO ISISIXHOSA EKUKHATHALELENI UMNTWANA OCHAPHAZELEKE KWIMITHAMBO-LUVO, AZE AFUMANE UBUNZIMA KULWIMI NOKUNXIBELELANA NABANYE)

Mzali / mlondolozi obekekileyo

Ingaba uziva ungenabani kolu hambo lokukhulisa umntwana wakho one-ASD (UXinzelelo lweMithambo-luvo oluhamba nokufumana ubunzima kulwimi nokunxibelelana nabanye)?

Ingaba uyayiqonda intsingiselo ye-ASD?

Ingaba unovakalelo lokuba umntwana wakho wohlukile kwabanye abantwana?

Ingaba ufumana ubunzima ekunxibelelaneni nomntwana wakho?

Ingaba unalo uvakalelo lokuxhaswa kwakho ngabantu abakwindawo ohlala kuyo?

Ndingathanda ukukunika ithuba lokuba yinxalenye yeqelana lengxoxo nabanye abazali abanokuba novakalelo olufanayo nolwakho.

****ISAZISO: izoba khona imali yezithutho ezizokusa eskolweni ne mail eyokugoduka**

Eli ingalithuba lokwabelana:

- *ngebali lakho nangeengcinga zakho,*
- *ngeentlungu zakho nezinto ezincomekayo,*
- *uloyiko lwakho namathemba onawo,*
- *izinto ezikukhathazayo nenkxaso* – kwindawo ekhuselekileyo apho uhlala khona.

Kuza kufuneka wenze oku:

- Ukwazi ukubakhona ngoMgqibelo omnye okanye ngecawe (bona ukhetho olungezantsi) ube kwiiseshoni ezimbini zeqela ezizoba iiyure ezimbini okanye ezintanthu.
- uphendule imibuzo uze ube yinxalenye yeengxoxo ezimalunga neASD kunye noluntu,
- uthathe inxaxheba kumsetyenzana wobugcisa oza kugunyazisa ukuba umntu ngamnye abalisele abanye imbali yobomi bakhe,
- utyikitye isivumelwano semfihlo esimalunga nokuyigcina iyimfihlo ingxoxo yamaqela kuquka namagama amalungu amaqela, - usithethe kwaye usiqonde isiNgesi.

saam vorentoe · masiye phambili · forward together

Fakulteit Opvoedkunde I Faculty of Education

Departement Opvoedkundige Sielkunde | Department of Educational Psychology

Privaatsak X1, Private Bag X1, Matieland, 7602

Tel: +27 21 808 xxx | Faks | Fax: +27 21 808 xxx | www.sun.ac.za

***CELA UBUYISELE ESIKOLWENI**

Ukuba ngenene lithuba ofuna ukulisebenzisa eli, nceda ubhale igama lakho kule bhokisi ilapha ngezantsi **iluhlaza**:

Ndiyasamkela esi simemo:	
*Nceda ugqithise neenombolo zakho zomnxeba/ Zeselulafowuni:	

Ukuba **awunawo** umnqweno wokulisebenzisa eli thuba, nceda ubhale igama lakho kule bhokisi ilapha ngezantsi **ibomvu**:

Ndiyasilandula esi simemo:

Abazali abaye basamkela isimemo, kuza kuqhagamshelwana nabo baze bathunyelwe nezinye iinkcukacha. Ukuba unemibuzo engeminye okanye ungathanda ukufumana ulwazi oluthe veje, nceda ungathandabuzi ukuqhagamshelana nam. Iinkcukacha zam zilapha:

uSinéad Comninos weYunivesithi yaseStellenbosch

Iselulafowuni: *0832330457*

I-Email: *sineadcomninos@gmail.com*

Enkosi ngokuzinika ithuba lokufunda oku. Ndiyathemba ukuba ndiya kuva kuwe kungekudala.

Ngemibuliso,

Sinéad

Ndicela uphendule lemibuzo:

isiNgesi ndiyasiva kakhule. Ndiyakwazi nokusithetha kakuhle. ☐

isiNgesi andisivi kakuhle. Andikwazi nokusithetha kakuhle. ☐

Ngamanye amaxesha ndiyakwazi ukisiva nokuusithetha isiNgesi. ☐

_____

Inkcubeko yam sisiXhosa. ☐

Inkcubeko yam ayisosisiXhosa. ☐

_____

Umntwana wam uneASD. ☐

Umntwana wam akanaASD/akanayo iASD. ☐

_____

Ndikhetha ukudibana ngoMqibelo. ☐

Ndikhetha ukudibana ngeCawe. ☐

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APPENDIX D

CONSENT FORMS: ENGLISH VERSION AND XHOSA VERSION

CONSENT TO PARTICIPATE IN RESEARCH

XHOSA-SPEAKING PARENTS' EXPERIENCES OF CARING FOR A CHILD WITH AUTISM SPECTRUM DISORDER

Dear potential participant

My name is Sinéad Comninos, a student from Stellenbosch University. I am currently in the process of completing my master's degree in educational psychology at the Department of Educational Psychology. I would like to invite you to take part in a focus group[3] discussion with other parents, who are also caring for children with Autism Spectrum Disorder. The results of this research project will assist me in completing my research project (thesis).

Please take some time to read the information presented below. It will describe and explain the details of this research project. If further detail and/or an explanation is needed, feel free to contact me. My contact details are listed in section 8.

Your choice to be part of the focus group discussion is **entirely voluntary** and **you are free to withdraw from the research process at any time**. If you do choose to not take part- at

[3] A focus group consists of five to ten participants who have something in common with one another- in this case, a child with Autism Spectrum Disorder. The researcher will ask semi-structured questions to facilitate the discussion taking place between the participants/parents in the group.

any time during the study, I can ensure you that it will not affect you negatively in any way whatsoever. You can let the researcher know via Whatsapp, SMS or Email.

1. PURPOSE OF THE STUDY

The purpose of this research project is:

1) To explore and understand the experiences of Xhosa-speaking parents who care for children with Autism Spectrum Disorder.
2) To look at what role the community plays in contributing to and influencing the parents' experiences.
3) To assist in creating a form of support within the Autism Spectrum Disorder community.

2. PAYMENT FOR PARTICIPATION

A transport fare of R40,00 is available for potential participants to access the research site- the school, for the focus group discussion. There will be no further financial support that will be offered to you. Participation is voluntary.

3. PROCEDURES OF THE STUDY

If you choose to partake, you will be asked to do the following:

1) To **carefully read through and sign the consent form**. The consent form can be returned before (via Whatsapp or email), or on the day of the focus group. There will be extra printouts of this form available at the focus group discussion for those who lose or forget their form.
2) **To fill in a short biographical form** attached to the consent form. Assistance with filling in the form will be available- if needed, on the day.
3) **To take part in a focus group discussion.** The researcher and participants will engage in a **discussion and an activity,** based on your experiences of Autism Spectrum Disorder in your community. This will take place over **<u>one</u> Saturday or Sunday** of two sessions each, which will take about 2-3 hours**.**

4) All precautions will be put in place to prevent contraction of COVID-19. The participant will be **asked to complete a health check** before entering the venue: https://healthcheck.higherhealth.ac.za/login/?next=/

5) With permission, the focus group discussions **will be recorded, only for the researcher's purposes.** This will stay highly confidential[4]. A translator/co-assistant will be present throughout the focus group discussions. Her role is to help with writing notes and other admin on the days of the focus group discussion. She will be writing down body language and gestures while you respond. She will also assist with prepping the venue and packing out of the refreshments, helping you sign in, hand out art materials and other important papers. The assistant is fluent in Xhosa and English and will only assist with translation if it is needed. She will only be present with your permission (*see at the end of the document and circle "Yes or No"). She will be asked to sign a confidentiality agreement. She/he will not share any details about the participants or the focus group discussion with anyone.

6) **A practical guide** for dealing with Autism Spectrum Disorder will be shared with each participant after the focus group discussions.

Additionally, the **transcriber** who writes down the discussions from the audio recordings, will be asked to sign a **confidentiality agreement**. The data collected will be summarised and integrated into the research project. The researcher will then provide a hard copy of the summary of the results of the data to the participants. **You will be asked to make suggestions or any changes on the transcriptions that could make the information more accurate**-if needed. The transcriptions and audio recordings will be stored in a secure place. Data will be kept for 5 years.

[4] Confidential: Meant to be kept secret or private.

4. POTENTIAL RISKS

All group members/ participants will be asked to keep the information shared within the group discussion confidential and will sign an agreement. You will be asked questions that might trigger some emotions that could lead to emotional distress. This will be dealt with within the focus group with the assistance of the researcher's therapy skills. In section 9, contact details of a free counselling service will be provided, if, in the rare event, you might need further support. You will be reminded of this opportunity again, at the end of the focus group sessions.

5. POTENTIAL BENEFITS TO PARTICIPANTS AND THE COMMUNITY

Both, participants, and the community will benefit from being involved in this study. Firstly, it is the hope of the researcher that the formation of the focus group will become **a support group** for the parents who have children with ASD, within the Xhosa-speaking community. Secondly, through the discussions and activity, the participants might become **aware and gain more insight into their own experiences** and others, and then be able to **share this information** with their neighbours and community.

In the third place it might **empower** the participants to take-action and provide more support for one another, deducing the possible stigma. Lastly, a practical information booklet based on Autism Spectrum Disorder will be provided for all participants.

6. CONFIDENTIALITY

Any information and responses received from the focus group discussion and the art activity will be anonymous and confidential. The school and school community will also be kept anonymous. The only time that the information would be shared, is in the rare event that it is required by law. All names of the participants, including the school, will be anonymised by assigning pseudonyms[5].

The audio recordings and transcriptions will be stored on the researcher's computer and shared with her supervisor, Ms Carla Feenstra. It will be stored on one online platform (Google

[5] A name that someone uses instead of his/ her real name.

Drive) and the researcher's hard drive. Both platforms will be protected with a password that is only known to the researcher and her supervisor. The audio recording will be transcribed by a transcriber and will be sent already anonymised with pseudonyms.

The findings of this research will be reported and published in a master's thesis that does not contain any data to identify the participants or the school. Any information that can identify participants will be erased from the researcher's computer, cell phone and Google Drive once the thesis has been completed.

7. RIGHTS OF RESEARCH PARTICIPANTS

You, as the participant have rights, and this is respected throughout this research project. If you have questions about your rights as a research participant, you may contact Mrs Maléne Fouché at the Division for Research Development: mfouche@sun.ac.za or 0218084622.

8. COVID-19 PRECAUTIONS

Due to the COVID-19 pandemic that has been present and continues to be for people all over the world; **careful precautions will be put in place for the focus groups.** The venue and any other materials or tools used will be sanitised before you arrive and after the focus group sessions. At arrival, you will be asked to complete a health screening form, your hands will be sanitised, and your temperature will be taken and recorded before entering the venue. Masks will always have to be worn- extra masks will be provided at the door.

Only participants that show no risk of infection or infecting others with the virus will be allowed to enter the venue. The group will be placed 2 meters from one another during discussion and the art activity. The researcher will always also adhere to the social distancing guidelines and keep 2 meters away from participants and wear a mask. As a further precautionary measure to safeguard you as participants, and the public, your contact details will be written down. If there is a case of COVID with one of the participants after the research project, the participants can be contacted and can self-isolate. The contact details of the participants will not be used for the research project and will be destroyed within a month of the last focus group session.

8. CONTACT DETAILS OF RESEARCHERS

If you have any questions or worries about the research project, please feel free to contact the researchers:

Sinéad Comninos

0832330457 or sineadcomninos@gmail.com

Carla Feenstra (Supervisor)

0218082319 or carlaf@sun.ac.za

9. CONTACT DETAILS OF SUPPORT SERVICE

Good Hope Psychological Services

(GHPS)

STELLENBOSCH

DIRECTIONS

Stellenbosch Provincial Hospital

Merriman Avenue, (0)21 887 7913

ghps@telkomsa.net

PAARL

DIRECTIONS

TC Newman Memorial Hospital

36 Rosary, Charleston Hill

(+27) 21 877 6400

PLEASE RETURN TO THE SCHOOL OR SINEAD

10. PARTICIPANT'S STATEMENT

I, _____ agree to take part in this research project based on iLizwe lam (My world): Xhosa-speaking parents' experiences of caring for a child with Autism Spectrum Disorder, with the researcher Sinead Comninos.

I understand:

- that taking part in this research project is my choice (voluntary) and I may choose to withdraw at any time during the research process;
- what is described in the consent form and am comfortable with the language it is written in;
- that I have had the chance to ask any questions and that my questions have been answered;
- that a translator/assistant will be present during the focus group discussions and will keep all names and information confidential;
- that all my information will be kept confidential and private;
- that precautions need to take place due to COVID-19;
- that all group members' identities and information need to be kept confidential.

Please choose one option and place a X in the box below:

I **do want** to take part in the research project. ☐

I **do not** want to partake in the research project. ☐

I agree to having a translator/assistant present during the focus group. **Y / N**

Signed on _____ (date) at _____ (place)

Researcher to sign:

I affirm that I have explained the information in this document and have answered any questions that were asked- with assistance from the co-assistant/ translator (if needed).

*****PLEASE RETURN TO THE SCHOOL OR SINEAD***

BIOGRAPHICAL INFORMATION:

Full name:	
Male or Female:	
Date of birth:	
Role in family (mother, father, guardian, grandparent, elder sibling, aunt/ uncle):	
Number of children with ASD:	
Age of child(ren) with ASD:	
Languages:	

CONSENT FORM: XHOSA VERSION

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

IMVUME YOKUTHATHA INXAXHEBA KUPHANDO

XHOSA-SPEAKING PARENTS' EXPERIENCES OF CARING FOR A CHILD WITH AUTISM SPECTRUM DISORDER

(AMAVA ABAZALI ABANTETHO ISISIXHOSA EKUKHATHALELENI UMNTWANA OCHAPHAZELEKE KWIMITHAMBO-LUVO, AZE AFUMANE UBUNZIMA KULWIMI NOKUNXIBELELANA NABANYE)

Mthathi-nxaxheba obekekileyo

Igama lam nguSinéad. Ifani yam nguComninos, kwaye ndingumfundi kwiYunivesithi yaseStellenbosch. Ndisecicini lokugqibezela izifundo zam zesidanga seemastazi kwizifundo zenzululwazi ngezengqondo kwiSebe leSayikholoji kwezeMfundo. Ndingathanda ukukumema ukuze uthathe inxaxheba kwingxoxo yeqela labantu abambalwa[6] eliza kuquka abanye abazali abakhathalela nabagcina abantwana abachaphazeleke kwimithambo-luvo, bantwana abo bafumana ubunzima kulwimi nasekunxibelelaneni nabantu. Iziphumo zalo msebenzi wophando ziza kundinceda ekuqukumbeleni izifundo zam zophando (ithisisi).

Nceda uziphe ithuba elaneleyo oku kuthiwe thaca ngezantsi apha. Kuza kukunika inkcazo nengcaciso yalo msebenzi wophando. Ukuba zikho iinkcukacha ezizezinye ezidingekayo,

[6] Iqelana lengxoxo kuphando lubandakanya abathathi-nxaxheba abamalunga nesihlanu ukuya kwabalishumi, nabafana ngento ethile – ngokolu phando ke, baya kufana ngokuba nomntwana onoXinzelelo okanye uphazamiseko kwimithambo-luvo, nto leyo imchaphazela kulwimi nokunxibelelana nabantu. Umphandi uza kubuza imibuzo engalandeli mgaqo uthile ncam, ngeenjongo zokukhuthaza ukuqhubeka kwengxoxo phakathi kwabathathi-nxaxheba/abazali abakwelo qelana lengxoxo.

musa ukuthandabuza ukuqhagamshelana nam. Iinkcukacha zam zonxibelelwano zidweliswe kwicandelo 8 ngezantsi apha.

Umnqweno wakho wokuba yinxalenye yeqelana lengxoxo kolu phando **ayisosinyanzelo tu kwaphela** kwaye **unakho ukuzikhwebula kwinkqubo yolu phando nangaliphi na ixesha.** Ukuba ukhetha ukungathathi nxaxheba – xa sele kuphakathi luqhuba uphando, ndiyakuqinisekisa ukuba oko akuyi kukuchaphazela kakubi nangaluphi na uhlobo. Unakho ukumchazela umphandi ngokumthumelela umyalezo kula majelo: kuWhatsapp, ngeSMS okanye iEmail.

1. IINJONGO ZOPHANDO

Injongo yolu phando yile:

1) Ukuphicotha nokuqonda amava abazali abangamaXhosa abakhathalela abantwana abanoXinzelelo lweMithambo-luvo, kuphele kuchaphazeleka ukusebenzisa kwabo ulwimi nokunxibelelana nabantu.

2) Ukuqwalasela indima edlalwa luluntu ekubeni negalelo okanye ekongezeni kula mava aba bazali.

3) Ekuncediseni ekusungulweni kwenkxaso ethile kummandla woXinzelelo lweMithambo-luvo emntwaneni.

2. PAYMENT FOR PARTICIPATION

A **transport fee of R40,00 is available** for potential participants to access the research site-the school, for the focus group discussion. There will be no further financial support that will be offered to you. Participation is voluntary.

3. INKQUBO YOPHANDO

Ukuba ukhetha ukuthatha inxaxheba, uza kucelwa ukuba wenze oku kulandelayo:

1) Ukuba **ufunde ngocoselelo uze utyikitye uxwebhu lwemvume yolu phando** uze uyibuyisele kumphandi phambi kokuqaliswa kwengxoxo yeqelana, kusuku olubekiweyo. Le fomu yemvume ingabuyiswa ngaphambi okanye ngosuku lokudibana kweqela logqaliselo (ithunyelwe kusetyenziswa uWhatsApp okanye i-imeyile). Kuza kubakho olunye ushicilelo lweekopi zale fomu kweza ngxoxo zamaqela ogqaliselo, ukuze zinikezwe kwabo banokuthi kanti bazilahlile okanye bazilibele emakhaya iifomu zabo.
2) **Ukugcwalisa ifomu emfutshane engolwazi ngobomi bakho** neqhotyoshelwe kuxwebhu lwemvume yolu phando. Ukuba umntu udinga ukucedwa ekugcwaliseni le fomu, olu ncedo luza kufumaneka kwangalo mhla wokufakwa kwezi fomu.
3) **Ukuthatha inxaxheba kwingxoxo yeqelana elichongiweyo.** Umphandi nabathathi-nxaxheba baza kuzibandakanya **kwingxoxo nakumsebenzi** ogxile kumava akho kummandla woXinzelelo lweMithambo-luvo emntwaneni. This will take place over **<u>one</u> Saturday** of two sessions each, which **will take about 2-3 hours.**
4) Onke amanyathelo okhuseleko aza kubakho kwangenx`engaphambili ukuze kunqandwe ukosuleleka ngugilikankqo we COVID-19. Umthathi-nxaxheba **uza kucelwa ukuba kukhangelwe inqanaba lakhe lempilo** phambi kokuba angene kwindawo ekuza kuxoxelwa kuyo: https://healthcheck.higherhealth.ac.za/login/?next=/
5) Ngemvume yabathathi-nxaxheba, iingxoxo zeqelana elichongiweyo **ziza kurekhodwa, kodwa oku kusetyenziswe kuphela ngumphandi.** Oku kuya kuba yimfihlo emandla ngaphandle kwamathandabuzo[7]. Umguquli okanye itoliki / umncedisi uya kuhlala ekho ngalo lonke ixesha lokuqhutywa kweengxoxo zeqelana elichongiweyo. Indima yakhe iza kuba kukuncedisa ekubhalweni

[7] Imfihlo: Kuthetha nantoni na egcinwa iyimfihlo okanye isekhusini.

kwamanqakwana nokwenza eminye imicimbi yolawulo kwezo ntsuku kuza kube kuqhutywa ngazo iingxoxo zeqelana elichongiweyo. Uza kubhala phantsi neentshukumo zomzimba nemijekulo eyenziwa ngabantu ngeli lixa bephendula. Uza kuncedisa nasekulungiseni indawo yengxoxo nasekupakishweni kwezidlwana zabathathi-nxaxheba, anincede ekubeni nityikitye xa nifika, aze aninike imisetyenzana yobugcisa kuquka namanye amaphepha abalulekileyo. Lo mncedisi uza kuba ngumntu osithetha ngokusulungekileyo isiXhosa nesiNgesi kwaye uza kunceda kuphela xa kufuneka etolikile, ukuba ke phofu sikho isidingo soko. Uza kubakho kuphela xa wena mthathi-nxaxheba uvuma ukuba abe kho.

- Naye uza kucelwa ukuba atyikitye uxwebhu lwemvumo yokuba kolu phando (*khangela ezantsi/ekugqibeleni kolu xwebhu uze ubiyele u-Ewe okanye u-Hayi). Lowo uzibandakanya kolu phando uza kutyikitya isivumelwano esiyimfihlo. Umphandi akayi kwabelana nabanye abantu ngeenkcukacha zabathathi-nxaxheba okanye iingxoxo zamaqela ogqaliselo.

6) **Malunga nesikhokelo esiza kusetyenziswa** ekuqwalaseleni imeko yoXinzelelo lweMithambo-luvo emntwaneni, esi sikhokelo kuza kukwabelwana ngaso nomthathi-nxaxheba ngamnye emva kokuqukunjelwa kweengxoxo zamaqelana achongiweyo.

Kananjalo, **umntu okhuphela oko kubhaliweyo** noza kubhala phantsi iingxoxo ezisuka kwizixhobo zokurekhoda, naye uza kucelwa ukuba atyikitye **isivumelwano esiyimfihlo**. Ukongeza koku, umphandi uza kukhuphela ngokubhala phantsi oko kurekhodiweyo, kwaye nolwazi oluqokelelweyo luza kushwankathelwa luze luqityaniswe kubuqu balo msebenzi wophando. Emva koko, umphandi uza kunikezela ngekopi engumqulu woshwankathelo lweziphumo lweenkcukacha zolu phando kubathathi-nxaxheba. Ushicilelo olubhaliweyo lweengxoxo kunye neengxoxo ezirekhodiweyo ziza kugcinwa kweyona ndawo ikhuselekileyo. Ulwazi luza kugcinwa isithuba seminyaka emi-5.

4. UBUNGOZI OBUNOKUVELA

Onke amalungu eqela/abathathi-nxaxheba baza kucelwa ukuba ulwazi ekuza kukwabelwana ngalo luphelele apha emaqeleni engxoxo, angadizwa naphi na, kwaye kuza kutyikitywa isivumelwano esimalunga noku. Uza kubuzwa ke nemibuzo enokuvuselela uvakalelo oluthile olunokukhokelela kunxunguphalo. Oku ke kuza kulungiswa kwalapha kwiqela lengxoxo ngoncedo lwezakhono anazo umphandi zokuthomalalisa unxunguphalo. Kwicandelo 9, kuza kunikezelwa ngeenkcukacha zonxibelelwano lweenkonzo zenkxaso xa kuthe kwavela unxungaphalo, ukuba kunokwenzeka kudingeke uncedo olumandla, nangona amathuba okwenzeka koku ekhangeleka emfiliba. Uza kuphinda ukhunjuzwe ngeli thuba kwakhona, emva kweengxoxo zamaqela achongiweyo.

5. INZUZO ENOKUZUZWA NGABATHATHI-NXAXHEBA NALULUNTU NGOKUBANZI

Ikho into enokuzuzuwa ngabathathi-nxaxheba noluntu ngokubanzi kolu phando. Okokuqala, ngumnqweno womphandi ukuba iqelana lengxoxo eliye lasungulwa liphele lisiba **liqela lenkxaso** kubazali abanabantwana abane-ASD, kwiindawo ekuhlala kuzo abantu abantetho isisiXhosa. Okwesibini, ngokubandakanyeka kwezi ngxoxo nemisebenzi yophando, kuyathenjwa ukuba abathathi-nxaxheba bangazuza **ulwazi kwanengqiqo ephangaleleyo ngokuphathelele kumava abo** nawabanye, baze bakwazi **nokwabelana ngolu lwazi** nabamelwane babo kwanoluntu ngokubanzi.

Okwesithathu, oku **kungaxhobisa** abathathi-nxaxheba ekubeni bakwazi ukwenza amanyathelo kwaye babaxhase ngakumbi abanye, nto leyo iya kunceda ekuncitshisweni kokubekwa kwebala okunokuvela. Okokugqibela, incwadi ecace ngqo emalunga noXinzelelo lweMithambo-luvo, iza kunikezwa kubo bonke abathathi-nxaxheba.

6. IMFIHLO

Naluphi na ulwazi kwaneempendulo ezifunyenwe kwiingxoxo zamaqela achongiweyo, kuquka nemisebenzi yobugcisa, luza kugcinwa iyimfihlo kwaye namagama awayi kuchazwa. Isikolo kwanendawo esikuyo isikolo, nazo aziyi kuchazwa okanye aziyi kubhencwa. Linye kuphela ilixa apho ulwazi lunokudandalaziswa khona, phofu namathuba okwenzeka koku anqabe oku

kwezinyo lenkukhu, kuxa ulwazi lufunwa ngabomthetho kuphela. Onke amagama abathathi-nxaxheba, kuquka nelesikolo, aya kufihlwa ngokuthi kusetyenziswe amagama aqwetyiweyo[8].

Ushicilelo lweengxoxo ezirekhodiweyo kwanamaxwebhu abhalwe aze akhutshwelwa koko kurekhodiweyo ziza kugcinwa kwikhompyutha yomphandi kuze kwabelwane ngazo nekhankatha lolu phando kuphela, khankatha elo linguNksk Carla Feenstra. Oku kuza kugcinwa kumjelo womnathazwe omnye kuphela (*iGoogle Drive*) nakuvimba wokugcina ulwazi lwekhompyutha yomphandi kuphela. Bobabini aba vimba baza kukhuselwa ngekhowudi eyimfihlo esetyenziselwa ukuvula ifayile kwikhompyutha, khowudi leyo iza kukwaziwa ngumphandi nekhankatha lakhe kuphela. Oko kurekhodwe kwizixhobo zokurekhoda xa umntu ethetha, kuza kushicilelwa ngumshicileli kwaye kuza kuthunyelwa sele efihliwe amagama abathathi-nxaxheba, koko kuvela amagama angengawo okanye aqwetyiweyo kuphela.

Iziphumo ezivele kolu phando ziza kudandalaziswa zize zishicilelwe kwithisisi yeemastazi engazi kuquka naluphi na ulwazi oluza kuchonga abathathi-nxaxheba okanye isikolo. Naluphi na ulwazi olunokukhokelela ekuchongeni abathathi-nxaxheba luya kucinywa kwikhompyutha yomphandi, kwifoni yakhe yesandla nakumjelo we-intanethi iGoogle Drive zisuka nje emva kwethisisi.

7. AMALUNGELO ABATHATHI-NXAXHEBA BOPHANDO

Wena, njengomthathi-nxaxheba unamalungelo, kwaye oku kuhlonitshiwe kuyo yonke inkqubo yolu phando. Ukuba kukho imibuzo onayo malunga namalungelo akho njengomthathi-nxaxheba kolu phando, unakho ukuqhagamshelana noNksk Maléne Fouché kwiCandelo loPhuhliso loPhando: mfouche@sun.ac.za okanye 0218084622.

[8] Igama elisetyenziswa ngumntu endaweni yegama lakhe lamanyhani.

8. AMANYATHELO OKHUSELEKO NGOKUPHATHELELE NECOVID-19

Ngenxa kagilikankqo we-COVID-19 okhoyo nosele eyinxalenye yobomi babantu kwihlabathi jikelele; kuza kubekwa amanyathelo okhuseleko agxile kwinkathalo ngalo bhubhane phambi kokuba kuqaliswe ngeengxoxo zamaqelana achongiweyo. Indawo yeengxoxo, izixhobo nazo zonke ezinye izinto eziza kusetyenziswa, ziza kutshizwa ngezikhuseli zococeko phambi kokuba ufike nasemva kokuqukunjelwa kwendibano yamaqela engxoxo. Xa kufikwa, uza kucelwa ukuba ugcwalise uxwebhu lokuhlola impilo, kuza kutshizwa izandla zakho ngesikhuseli sokucoca intsholongwane enokubakho, kwaye neqondo lobushushu bakho liza kuhlolwa lize libhalwe phantsi phambi kokuba ungene kwindawo yengxoxo. Iimaskhi kuza kufuneka zinxitywe oko zingakhululwa – kuza kunikezwa nezinye iimaskhi emnyango.

Kuza kuvunyelwa kuphela abathathi-nxaxheba abangabonisi zimpawu zakosuleleka sisifo okanye zakosulela abanye ngesifo ekubeni bangene kwindawo yeengxoxo zophando. Iqela liza kuhlaliswa ngokuthi umntu abekwe qelele kangangeemitha ezimbini ukusuka komnye ukuya komnye ngeli lixa kuqhutywa iingxoxo kusenziwa nemisetyenzana yobugcisa. Nomphandi ngokwakhe uza kuhlala ezithobela izikhokelo zokumiswa okanye ukuhlaliswa qelele kwabantu, kwaye naye uya kuba kumgama oziimitha ezimbini ukusuka kubathathi-nxaxheba, kananjalo uza kuhlala enxibe imaskhi. Okongezelekileyo okuza kwenziwa ukuqinisekisa ukuba wena njengomthathi-nxaxheba ukhuselekile, kuquka nabo bonke abantu, iinkcukacha zakho zonxibelelwano ziza kubhalwa phantsi. Ukuba kuye kwakho inkcazo malunga nokuba omnye wabathathi-nxaxheba wosulelekile sisifo iCovid emva komsebenzi wolu phando, kuya kuba lula ukuqhagamshelana nabathathi-nxaxheba kwaye kugunyaziswe ukuba bazicebule babe phantsi konyango. Iinkcukacha zonxibelelwano zabathathi-nxaxheba aziyi kusetyenziselwa olu phando, kwaye ziya kutshatyalaliswa kwisithuba senyanga emva kwendibano yokugqibela yengxoxo yeqelana elichongiweyo.

9. IINKCUKACHA ZOQHAGAMSHELWANO ZABAPHANDI

Ukuba kukho imibuzo ofuna ukuyibuza okanye unenkxalabo malunga nalo msebenzi wophando, nceda ungathandabuzi ukuqhagamshelana nabaphandi:

Sinéad Comninos

0832330457 okanye sineadcomninos@gmail.com

Carla Feenstra (Ikhankatha lophando)

0218082319 okanye carlaf@sun.ac.za

10. IINKCUKACHA ZOPHANDO ZEENKONZO ZONKXASO

Good Hope Psychological Services (GHPS)

STELLENBOSCH

INKCAZELO NGENDLELA

Stellenbosch Provincial Hospital

Merriman Avenue

+ 27 (0)21 887 7913

ghps@telkomsa.net

PAARL

INKCAZELO NGENDLELA

TC Newman Memorial Hospital

36 Rosary, Charleston Hill

(+27) 21 877 6400

11. ILIZWI LOKUVUMA KOMTHATHI-NXAXHEBA

Mna, _____ ndiyavuma ukuthatha inxaxheba kulo msebenzi wophando ujolise kwiLizwe lam

(*My world*) nonesi sihloko sophando: Amava abazali abantetho isisiXhosa abakhathalela okanye abagcina abantwana abanoXinzelelo lweMithambo-luvo nabaphela bechaphazeleka kulwimi nokunxibelelana nabantu, phando olo baza kusebenza kulo kunye nomphandi onguSinead Comninos.

Ndiyayiqonda: o into yokuba ukuthatha inxaxheba kulo msebenzi wophando kukuzikhethela kwam (andinyanzelwanga), kwaye ndinelungelo lokukhetha ukuzikhwebula kwinkqubo yolu phando nangaliphi na ixesha;

- o into yokuba ndicacelwe koko kuchazwe kuxwebhu lwemvume kwaye andinangxaki ngolwimi ebhalwe ngalo le fomu;
- o into yokuba ndilifumene ithuba lokubuza nayiphi imibuzo kwaye imibuzo yam iye yaphendulwa;
- o into yokuba umphandi/umncedisi uza kubakho ngexesha ekuqhutywa ngalo iingxoxo zamaqelana kwaye onke amagama nolwazi ziza kugcinwa ziyimfihlo;
- o into yokuba zonke iinkcukacha zam ziza kugcinwa ziyimfihlo kwaye aziyi kubhencwa sidlangalaleni; o into yokuba kumele kuthatyathwe amanyathelo okhuseleko ngenxa yeCOVID-19; o into yokuba amagama neenkcukacha zawo onke amalungu eqela lengxoxo ziza kugcinwa ziyimfihlo.

Nceda ukhethe into ibe nye uze ubeke u-X kule bhokisi ingezantsi:

Ndiyafuna ukuthatha inxaxheba kulo msebenzi wophando. ☐

Andifuni kuthatha nxaxheba kulo msebenzi wophando.

Ndiyavuma ukuba kubekho umguquli/umncedisi ngeli lixa amaqela ogqaliselo ekwingxoxo. **Y / N** ☐

Ityikitywe nini _____ (umhla) e _____ (indawo)

Intsayino-gama yomphandi:

Ndiyaqinisekisa ukuba ndiluchaze lonke ulwazi kolu xwebhu kwaye ndiyiphendule yonke imibuzo ka (Igama nefani yomthathi-nxaxheba): _____ Imibuzo ebuziweyo – ngokuncediswa ngumncedisi/umguquli (ukuba bayafuneka).

Intsayino-gama yomthathi-nxaxheba: _____

Igama neFani lomphandi: _____

Intsayino-gama yomphandi: _____

IINKCUKACHA ZOMTHATHI-NXAXHEBA:

Igama:	
INene okanye iNenekazi:	
Umhla wokuzalwa:	
Indima kusapho (umama, utata, umlondolozi, oomawokhulu, umkhuluwa okanye udade omkhulu, umakazi okanye udadobawo / umalume okanye ubawokazi):	
Inani labantwana abane-ASD:	
Unyaka okanye iminyaka yabantwana abane-ASD:	
Iilwimi:	

APPENDIX E

FOCUS GROUP PROGRAMME AND SEMI-STRUCTURED INTERVIEW QUESTIONS

FOCUS GROUP PROGRAMME		
The researcher will act as facilitator in the group discussions. Semi-structured interview questions will only be an initial guideline for the researcher to start and continue the discussions. Interpreter will be present.		
Seating:	Semi-circle/Circle format	
Materials:	Extra copies of consent letters, practical guidebook, focus group programme; transport money, A3 paper, pastels and pencil crayons, tables, chairs, kettle, lunch packs, coffee, tea, sugar, cardboard cups, cutlery, notebooks, voice recorder (Zoom), hand sanitiser, laptop, extra masks, thermometer, name tags/labels.	
Participants:	± 6	
Duration:	4 hours and 30 minutes	NOTES:
10:00-10:15 SIGN IN (± 15 minutes)	**1. Welcoming and COVID-19 preventative steps:** Sign in, sanitise, temperature taking, symptoms check list.	
10:30-11:00 INTRODUCTION **(**± 30 minutes)	**2. Overview of topic** **3. Guidelines for focus group discussion and COVID-19 regulations** **4. Revise informed consent letter.** **5. Questions from participants** **6. Introduction of participants (facilitate building of rapport)** Name label: can choose alias or first name. Everyone in the group introduces themselves and tells the group how old their child with Autism is.	
11:00-12:30	**7. Instructions/ reflections:**	

RIVER OF LIFE ACTIVITY AND DISCUSSION (± 1 hour and 30 minutes: Instructions- 15m. Drawing- 30-40m. Discussion – 45m.	The River of Life (Joyce Mercer; adapted by The On Being Project) ● **Think and reflect about your life and the path you have taken. What shape has it taken? Think about the all the moments/ events and people who have shaped your journey so far.** ● **Follow guidelines on the River of Life attachment.** ● **Participants use ±30 minutes to complete their drawing.** **8. Discussion:** ● **The researcher will engage the group in a discussion of their activity (only those who are willing to share) and facilitate the process. The following questions could be used if guidance is needed:** - **Tell us about your picture.** - **How did you find the process/the activity? What stood out for you?** - **When did that happen?** - **How did it effect you?** - **How did it feel?** - **How was the community involved?** - **Who did you get support from?** - **How did you understand that?**	
12:30- 13:00 Lunch Break	**9. Break:**	

(± 30 minutes)	Already made sealed-off packs will be handed out to each participant for lunch. Coffee and Tea will be provided.	
13:00-14:00 DISCUSSION (± 1 hour)	**10. Focus group questions (semi-structured):** A. What are the Xhosa-speaking parents' perspectives of ASD and what is their daily experience of the diagnosis? 1. Tell us a story/about your child that has ASD. 2. What do you think Autism does/ is? How does it work? 3. How has Autism influenced your life: socially, physically, emotionally? 4. How did you feel when the doctor told you your child's diagnosis? What were you thinking? B. How do the Xhosa-speaking parents experience the knowledge and misconceptions (if any) of ASD within the community? 4. What did you call your child's difficulties before it was diagnosed? 5. What did other people within your community say it was? Did/ does the community see it the same way as you do? 6. How have people reacted to your child? Tell me a story/ example. 7. What do you think caused it? 8. What challenges have your child's Autism caused? 9. What do you fear most about it? C. What are the Xhosa-speaking parents' experiences of support and understanding within the community?	

	10. What support do you think your child should (should have) receive(d)? Who should be involved? 11. What influence does your culture have on this(support)? 12. What are your expectations from the community and society? 13. Is there anything that was not brought up in the discussion that is important to you, that you would like to discuss?	
14:00-14:30 CLOSURE (± 30 minutes)	● **Debrief, by reflecting on the discussions/ session with the participants.** ● **Thank participants for their time and contributions.** ● **Remind participants about them reviewing the results and findings of the thesis before submission and publication.** ● **Encourage continuation of focus group/ support group.** **11. Hand out practical guidebook and transport money**	

APPENDIX F

SCHOOL EMAIL REQUESTING PERMISSION

Gmail Sinead Comninos <sineadcomninos@gmail.com>

Sinead Comninos <sineadcomninos@gmail.com> 23 November 2020 at 13:50

To:

Dear

Thank you so much for taking the time to do this.

The title of my research study is: iLizwe lam (My world): Xhosa-speaking parents' experiences of caring for a child with Autism Spectrum Disorder

Here is a short summary of my research study:

The majority of psychological research tends to be more focused on the "individual as autonomous", whereas within the African world, the individual "coexists with the community, with spirits and with the ecological environment" (Berry, Poortinga, Segall, & Dasen, 2002, p. 106). There seems to be a gap in literature in understanding the perspective of the non-western world, as there has been little research done on ASD children and their parents within the African and Xhosa context.

The goal of this research study is to explore and better understand Xhosa-speaking parent's experiences and perceptions of their child that live with ASD. Secondly, to look at the possible influence the community's beliefs have on the outcome of management and support of the manifestation of ASD. It will contribute to further exploration into the African/ non-western perceptions of ASD research, which could lead to the development of more accessible and culturally friendly interventions that are appropriate for the Xhosa community.

Main research question is: How do Xhosa-speaking parents experience caring for their child with ASD within their community?

Research questions:
1. What are the Xhosa-speaking parents' perspectives of ASD and what is their daily experience of the diagnosis?
2. How do the Xhosa-speaking parents experience the misconceptions, if any, and knowledge of ASD within the community?
3. What is the Xhosa-speaking parents experience of support and understanding within the community?

A qualitative, basic interpretive design will be used. Participants will be selected using

purposive sampling. Parents from a school in Cape Town for ASD learners will be invited to participate in the study. Data collection will involve semi-structured discussions in focus groups. In order to integrate the study, the theoretical framework will be based on Bronfenbrenner's bioecological model.

I would like to ask if I could please complete data collection at I would like to form a focus group over a duration of two weekend days, with Xhosa-speaking parents of children with Autism Spectrum Disorder. Due to COVID-19 the group can be no more than 8 parents. The minimal participants for me would be no less than 4. I would need the cell phone numbers (suggested this) of those parents. The rest of the data collection process will be my responsibility.

Would it be possible to also use the school as a venue for the focus group over the 2 weekends?

All COVID precautions and guidelines will be followed very carefully.

Please let me know if there is any further information that will be required.

Thank you kindly.

Kind regards

Sinead Comninos

0832330457

2 attachments

Research approval letter.doc
215K

Consent form Final_SineadComninos.docx
80K

APPENDIX G

RIVER OF LIFE DIRECTIONS FOR FOCUS GROUP/INTERVIEW

River of life exercise:

(Adapted from Joyce Mercer and The Being Project)

* The activity will be explained with a visual drawing while it is explained/instructions are given.

1. Close your eyes and think back on your life so far. Now imagine your life was like a river- how would it look? What shape would it be- thick, thin, both? Would it be straight or curvy? Would it only curvy when things changed in your life or you changed? And if so, was it difficult or easy when those changes happened? Are there any rocks that have maybe fallen into your river that is stopping you from doing things or that have stopped your river from running because something bad happened in your life? Does the river run well in some places or does it run slowly and has little water? Are there trees or plants next to the river that have supported the river, or the river has supported the trees/ plants?

2. When you open your eyes, you will start to draw your river of life on the page given to you. - You can write the age and/ or dates next to the different places of your river to show when there were changes or bad or good things that happened. You can also write down the event/ what happened to change the shape of your river.

3. Think about any people that have been part of your life journey, that are still with you and that you have lost. Put this on your river of life drawing. It can be people that have influenced you- in a good or bad way, and it can also include your community or culture.

4. You can also show at what time in your life there was pain or sadness (yours or other people's). And what happens to the shape and water of the river? You can think about adding things that was happening in the world or in your community that could change your river of life.

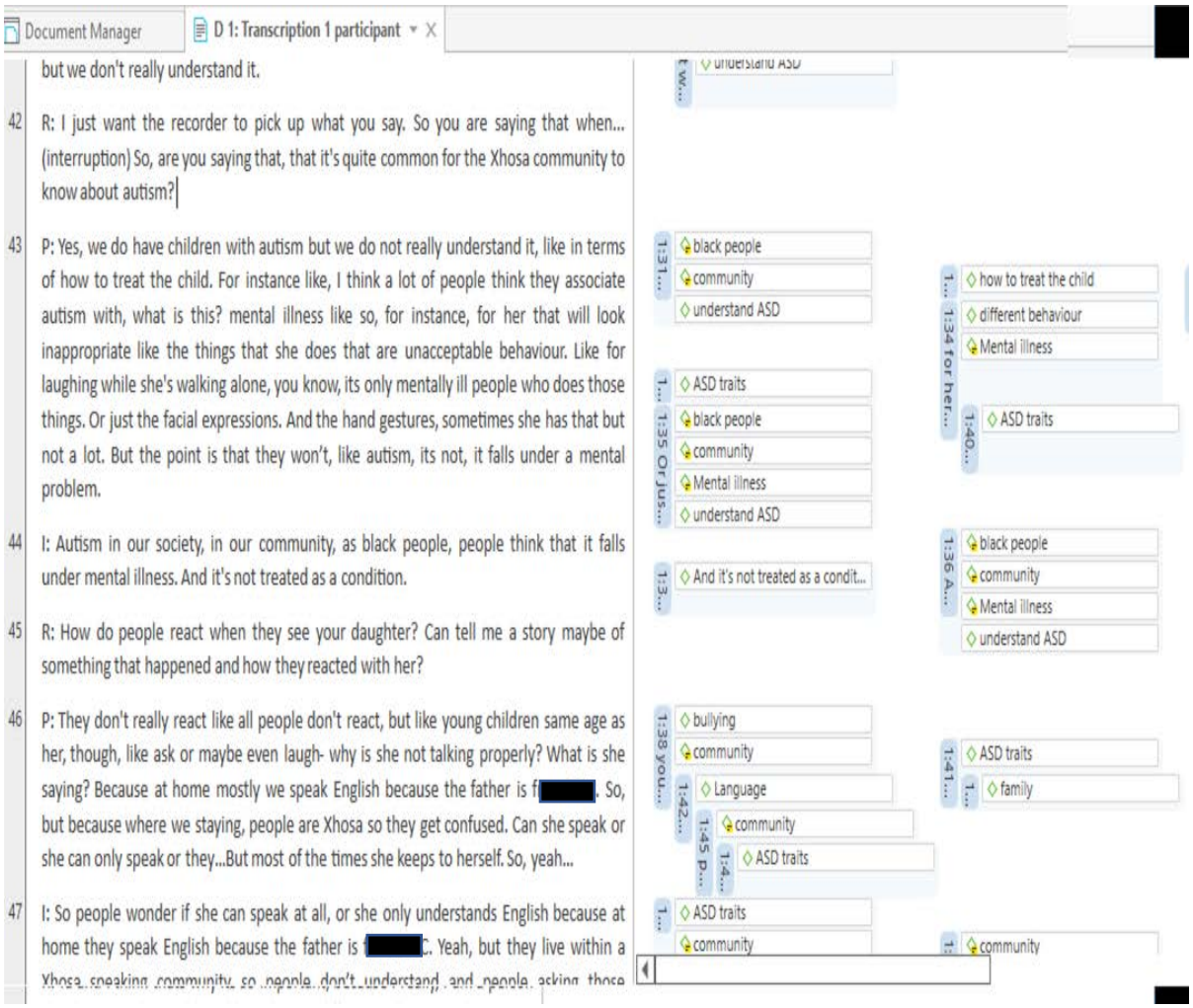
5. I want you to think about what beliefs and values you had that was important to you at different times in your life.

6. *Give participants time to complete their drawing. Tell them that if they would like to, they can share their river of life drawing with the group, if they feel uncomfortable sharing it, they can use it to look back on their life.*

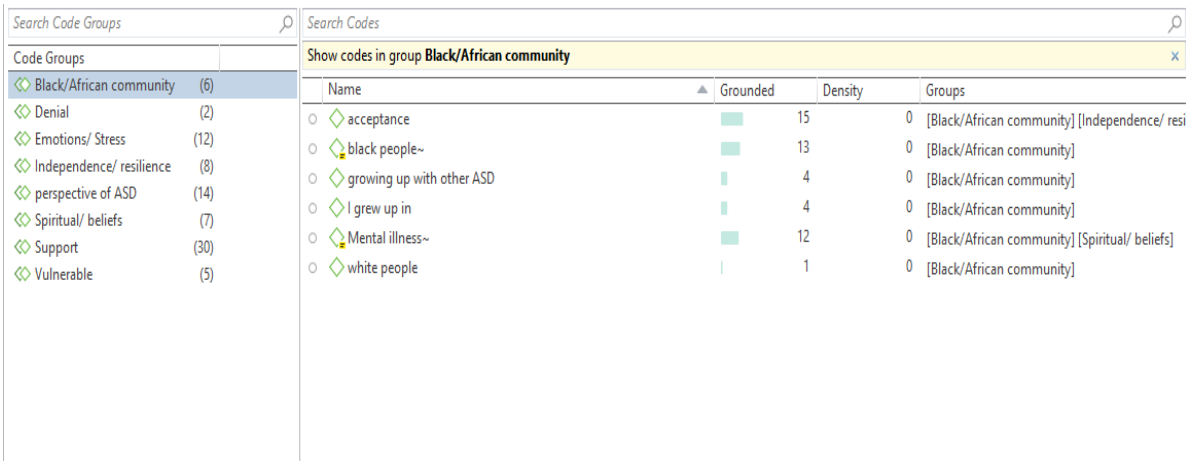
APPENDIX H

EXAMPLE OF TRANSCRIPTION WITH CODING

Initial phase



Finalising stages



APPENDIX I

WCED RESEARCH APPROVAL LETTER

Audrey.wyngaard@westerncape.gov.za
Tel: +27 021 467 9272
Fax: 0865902282
Private Bag x9114, Cape Town, 8000
wced.wcape.gov.za

REFERENCE: 20201110-9406
ENQUIRIES: Dr A T Wyngaard

Ms Sinead Comninos
32 Retief Street
Northern Paarl
7646

Dear Ms Sinead Comninos

RESEARCH PROPOSAL: ILIZWE IAM (MY WORLD): XHOSA-SPEAKING PARENTS' EXPERIENCES OF CARING FOR A CHILD WITH AUTISM SPECTRUM DISORDER

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **28 January 2021 till 23 September 2021.**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Dr A.T. Wyngaard at the contact numbers above quoting the reference number?
8. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

    The Director: Research Services
    Western Cape Education Department
    Private Bag X9114
    CAPE TOWN
    8000

We wish you success in your research.

Kind regards.
Signed: Dr Audrey T Wyngaard
Directorate: Research
DATE: 10 November 2020

APPENDIX J

DECLARATION OF EDITING

P.O. Box 955
Oudtshoorn
6620
Tel (h): (044) 2725099
Mobile: 0784693727
E-mail: dsteyl@polka.co.za

29 August 2021

TO WHOM IT MAY CONCERN

STATEMENT REGARDING LANGUAGE EDITING OF THESIS

Hereby I, Jacob Daniël Theunis De Bruyn STEYL (I.D. 5702225041082), a language practitioner accredited to the South African Translators' Institute (SATI), confirm that I have edited the language of the following thesis and submitted the edited version electronically to the author on 29 August 2021:

Title: iLizwe lam (My world): Xhosa-Speaking Parents' Experiences of Caring for a Child with Autism Spectrum Disorder

Author: Ms Sinead Comninos

Yours faithfully

J.D.T.D. STEYL

PATran (SATI)

SATI REGISTRATION NUMBER: 1000219